Barriers to and facilitators of the transition to adult care among HIV-infected youth in the Western Cape

by
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DECLARATION

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ABSTRACT

Background. South Africa has the highest rate of HIV-infection in the world, and with nearly one-third of all new HIV-infections occurring in the age group 15−24 years, adolescents and young people bear the burden of this disease. As children and young people move through their developmental stages, those living with chronic illnesses also move through the healthcare system, transitioning from paediatric services to adult services. Ideally, when those receiving paediatric care reach late adolescence (15–19 years) or early adulthood (19–25 years), they should transfer to adult care so that they can start managing their own health. However, in resource-limited settings like South Africa, little is understood of the transition process and the factors that may contribute to or hinder the process. As such, the aim of this study was to explore the barriers to and the facilitators of transition to adult HIV care among HIV-infected youths in the Western Cape from the perspectives of healthcare providers who provide paediatric and adult HIV healthcare services.

Methods. I used purposive sampling methods to recruit participants for this study. Data gathering included in-depth, semi-structured interviews with 24 healthcare providers (pharmacists (n=7), doctors (n=3), nurses (n=8), sisters (n=2), counsellors (n=1)) and three additional hospital staff (one data capturer and two administrative clerks). The interviews were audio-recorded and transcribed verbatim for the purposes of thematic analysis. I analysed the data using ATLAS.ti computer software. Further, I used an observation schedule to document the moment-by-moment occurrences in the patient waiting rooms of the two healthcare facilities included in this study.

Results. Four themes and 10 subthemes that captured participants' sentiments on the barriers to and facilitators of transition to adult care emerged from the data. The four themes were (1)

understanding and conceptualization of transition; (2) individual factors affecting transition; (3) healthcare system factors affecting transition; and (4) social factors affecting transition. Participants understood transition to mean different things, including a change in the medication regimen, a change of clinic or a change of doctor. Some were not familiar with the term. Barriers to transition included a lack of transition readiness, the unfriendly clinic environment, services gaps, a lack of knowledge about HIV, a lack of communication, adolescents' developmental stage, home environments and broad contextual issues (such as poverty and inequality, the breakdown of family, and stigma). Further issues were related to service provision, such as inadequate resources in the clinic, insufficient training, lack of policies, and fragmented services. Participants suggested that an increase in the number of healthcare professionals and the employment of younger staff could be of benefit. They also suggested that training and preparatory programmes could provide adolescents with adequate support and prepare them for transition. Participants furthermore proposed ongoing individual counselling sessions for transitioning adolescents as well as a tracking system for defaulters from adult clinics. Others suggestions included the creation of youth-friendly clinics with integrated healthcare systems only for youths; training of healthcare providers in adolescent medicine, and the creation of centres and programmes for youths in their communities. Participants also highlighted the importance of the implementation of continuous HIV awareness programmes and resources for HIV-infected youths and their families.

Conclusion. The findings from this study demonstrate that the transition to adult care is not always easy. Understanding the barriers to and facilitators of the transition to adult care will help guide informed initiatives and strategies that can improve the transition process from the paediatric to the adult healthcare setting. Targeting the needs of adolescents during the process of transition has the potential to improve adolescents' adherence to treatment and to promote long-term health outcomes.

OPSOMMING

Agtergrond. Suid-Afrika het die hoogste MIV-infeksiesyfer in die wêreld. Bykans een derde van alle nuwe MIV-infeksies betrek persone in die ouderdomsgroep 15–24 jaar, wat beteken dat adolessente en jong volwassenes grootliks die las van hierdie siekte dra. Soos kinders en jongmense deur hulle ontwikkelingsfases beweeg, moet diegene wat met kroniese siektes saamleef deur die gesondheidstelsel beweeg en algaande die oorgang van pediatriese dienste na volwasse dienste maak. Ideaal gesproke moet persone wat pediatriese dienste ontvang na volwasse sorg oorgaan wanneer hulle laat adolessensie (15–19 jaar) of vroeë volwassenheid (19–25 jaar) bereik, sodat hulle kan begin om hulle eie gesondheid te bestuur. In kontekste met beperkte hulpbronne, soos Suid-Afrika, is daar egter nog minder kennis oor wat hierdie oorgangsproses behels asook die faktore wat die proses kan ondersteun of kan verhinder. Die doel van hierdie studie was om die struikelblokke en die faktore wat die oorgang na volwasse MIV-sorg vergemaklik by MIV-besmette jeug in die Wes-Kaap uit die perspektief van MIV-gesondheidsdiensverskaffers van pediatriese en volwasse dienste te ondersoek.

Metodologie. Ek het doelgerigte steekproefnemingsmetodes gevolg om deelnemers vir die studie te identifiseer. Data-insameling het in-diepte, semigestruktureerde onderhoude met 24 gesondheidsorgverskaffers (aptekers (n=7), dokters (n=3), verpleegkundiges (n=8), susters (n=2), beraders (n=1)) en drie bykomende hospitaalpersoneel (een datavaslegger en twee administratiewe klerke) behels. Ek het klankopnames van die onderhoude gemaak en dit verbatim getranskribeer. Die data is ontleed met behulp van ATLAS.ti rekenaarsagteware. Ek het daarbenewens ’n observasieskedule gebruik om die oomblik-vir-oomblik gebeure in die pasiënt wagkamers van die twee deelnemende gesondheidsorginstellings te dokumenteer.

Resultate. Vier temas en 10 subtemas wat die deelnemers se sienings oor struikelblokke en faktore wat die oorgang na volwasse sorg vergemaklik weergegee het, het uit die data na vore gekom. Die vier temas was (1) verstaan en konseptualisering van oorgang; (2) individuele faktore wat die oorgang affekteer; (3) faktore binne die gesondheidsorgstelsel wat oorgang raak; en (4) maatskaplike faktore wat oorgang beïnvloed. Deelnemers het verskillende dinge onder oorgang verstaan, onder andere ’n verandering van die medikasieregimen, ’n verandering van kliniek, of ’n verandering van dokter. Sommige deelnemers was nie bekend met die term nie. Struikelblokke tot oorgang is geïdentifiseer as ontoereikende oorgangsgereedheid, die onvriendelike kliniekomgewing, die gapings in dienste, ’n gebrek aan kennis rakende MIV, ’n gebrek aan kommunikasie, adolessente se ontwikkelingstadium, huislike omstandighede, en breë kontekstuele faktore (soos armoede en ongelykheid, die verbrokkeling van die gesin, en stigma). Verdere probleme hou verband met dienslewering, soos ontoereikende hulpbronne by klinieke, onvoldoende opleiding, gebrekkige beleid, en gefragmenteerde dienste. Deelnemers was van mening dat ’n groter aantal gesondheidsorgwerkers en die indiensneming van jonger personeel van waarde kan wees. Hulle het ook gestel dat opleidings- en voorbereidingsprogramme aan adolessente ondersteuning kan bied en hulle kan voorberei vir die oorgang. Deelnemers het verder voorgestel dat adolessente wat besig is om die oorgang te maak deurlopende individuele berading moet ontvang en dat ’n naspoorstelsel uit volwasse klinieke tot stand gebring moet word om nienakomende adolessente te ondervang. Ander voorstelle was die vestiging van jeugvriendelike klinieke met geïntegreerde gesondheidsorgstelsels net vir die jeug; die opleiding van gesondheidsorgverskaffers in adolessente medisyne, en die vestiging van sentrums en programme vir die jeug binne hulle gemeenskappe. Die deelnemers het ook die belangrikheid van die implementering van deurlopende MIV-bewustheidsprogramme en hulpbronne vir MIV-besmette jeug en hulle gesinne beklemtoon.

Gevolgtrekking. Die bevindinge van hierdie studie wys dat die oorgang na volwasse sorg nie altyd maklik is nie. ’n Begrip van die struikelblokke en die faktore wat oorgang ondersteun kan leiding bied rakende ingeligte inisiatiewe en strategieë wat die oorgangsproses van pediatriese na volwasse gesondheidsorg kan vergemaklik. As die behoeftes van adolessente gedurende die oorgang aangespreek word, kan dit adolessente se nakoming van behandeling versterk, en sodoende hulle langtermyn gesondheidsorguitkomste verbeter.

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ABBREVIATIONS

AAP	American Academy of Paediatrics
ART	Anti-retroviral therapy
CHIPS	Collaborative HIV Paediatric Study
DoH	Department of Health
HCP	Healthcare professional
LMIS	Low and middle income settings
PLWH	People living with HIV/AIDS
SANACT	South African national AIDS council trust
SSA	Sub-Saharan Africa
UK	United Kingdom
UNAUC	United Nations African Union Commission
UNAIDS	Joint United Nations Programme on HIV/AIDS
UN	United Nations
UNICEF	United Nations Children's Fund
USA	United States of America
WHO	World Health Organization

CHAPTER 1

1.1 INTRODUCTION

Global efforts are aimed at ending the HIV/AIDS epidemic by 2030 (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2014; United Nations Children's Fund (UNICEF), 2018). However, this target may be difficult to achieve, especially for the age group 15–24 years, given the growing rates of HIV infection in this age group (Idele et al., 2014; Mark, Taing, et al., 2017; Slogrove, Mahy, Amstrong, & Davies, 2017; World Health Organization (WHO), 2016). UNICEF (2017) estimates there are 29 new infections every hour among adolescents aged 15−19 years globally. There are a large number of youths living with HIV/AIDS (PLWH) all over the world, and over 30% of new infections are estimated to occur among those aged 15–24 years (Slogrove et al., 2017; UNAIDS, 2016; UNICEF, 2017;2018; WHO, 2016).

Sub-Saharan Africa (SSA) has been identified as one of the regions with the highest prevalence (90%) of HIV-positive youths around the world with an estimated 1.3–2.2 million youths who have been infected perinatally (from mother to child) and behaviourally (through blood infection or sexual transmission) (Pantelic, Boyes, Cluver & Thabeng, 2018; Toska et al., 2017). Recent estimates suggest that there were 1.8 million adolescents in SSA living with HIV in 2015, of which 250 000 were new infections (UNAIDS, 2016). South Africa has the highest rate of HIV infection in the world, with nearly one third of all new HIV infections found in the age group of 15−24 years (Hodes, Cluver, Toska & Vale, 2018; Zanoni, Archary, Buchan, Katz, & Haberer, 2016).

The high HIV incidence is likely due to certain experiences and challenges that are specific to the adolescent developmental stage. For example, adolescents aged 15–19 years are confronted with a period of transition marked by pubertal development, sexual identity formation, social and cognitive maturation (Judd et al., 2017; Kail, Cavanaugh & Muller, 2019;

Mark, Amstrong, et al., 2017; Tepper, Zaner & Ryscavage, 2017). Negotiating these milestones can be challenging as it involves the wide exploration of sexuality. For example, evidence suggests that youths engage in sexual intercourse with multiple sexual partners and in unprotected sex (Cataldo et al., 2012; Toska et al., 2017). In addition, there is a high level of sexually transmitted infections (STIs), mental health issues, substance abuse and risky sexual behaviour among adolescents aged 15–19 years, thus placing them at increased risk of HIV infection (Madhombiro et al., 2019; Slogrove et al., 2017; Smit, et al., 2006; UNAIDS, 2014). Some adolescents (15–19 years) are reluctant to test for HIV, and when diagnosed as HIV positive, they are more likely to deny their status by refusing treatment or ceasing treatment (Johnson et al., 2017). The rise in the number of children vertically infected with HIV who have survived to adolescence also contributes to the increased prevalence of adolescents aged 15–19 years living with HIV (Dahourou et al., 2017; UNAIDS, 2016).

The terms “youth” and “adolescents” are used interchangeably in the literature. For example, in the African Youth Charter of (UNAUC, 2006) and South Africa’s National Youth Policy (2015–2020), “youth” is defined as anyone aged between 14 and 35 years of age. This large age range is used in an attempt to account for the historical inequalities of the past, such as the deficient education “older” youth received before South Africa transitioned to democracy (UNAUC, 2006). However, the United Nations (2008) refer to youths as those individuals ages between 15 and 24 years. Indeed, much of the global and local HIV literature use this age range to demarcate the youth (Dahourou, et al., 2017; Slogrove et al., 2017; UNAIDS, 2016; UNICEF, 2016; UNICEF, 2018). In keeping with this trend, I use the term youth and adolescent interchangeably throughout my thesis to refer to individuals aged between 15 years and 24 years.

The period of adolescence typically refers to the transitional stage of physical and psychological development that occurs in the period between puberty and legal adulthood (age of majority) (Kail et al., 2019; Steinberg, 2014). As youths transition through developmental stages,

those living with chronic illnesses also transition from paediatric healthcare services to adult services (Hart, Patel-Nguven, Merkley, & Jonas, 2019; Judd & Davies, 2018). When those receiving paediatric care reach late adolescence (15–19 years), or early adulthood (19–25 years), they are transferred to adult care in order for them to start managing their own health (Mark, Taing, et al., 2017; Tanner et al., 2018). However, the age of transition seems to differ across various settings. For example, in high-income settings like Europe, healthcare transition for adolescents with HIV most often takes place at or near 18 years of age (Collaborative HIV Paediatric Study (CHIPS), 2016; Philbin, Tanner, Ma, et al., 2017). In the United States of America (USA), HIV healthcare transition occurs anywhere between 18–25 years and often only when youths have reached their mid-twenties (Tanner et al., 2018; Tepper et al., 2017). In the United Kingdom (UK), the transition occurs between the ages of 17 and 27 years (Kim, Kim, McDonald, Fidler, & Foster, 2016). In low and middle-income settings (LMIS), like South Africa, it is estimated that youths enter the adult healthcare system at the age of 13 (Stefan & Van der Merwe, 2008). These examples highlight that there is no agreed-upon age of transition, and that there is a need to be sensitive to the age at which paediatric patients transition to adult care. Some high-income settings have clear protocols on transition, for example the USA and UK (Gilliam et al., 2011; Miles, Edwards, & Clapson, 2004; Wiener, Kohrt, Battles & Pao, 2011). These settings have taken a more comprehensive view of transition and have defined practices informed by developmental theory, for example engaging in early discussion about transition, skills building and collaborative transition teams (Hussen et al., 2015).

In South Africa, there is no adolescent transition policy (Kung et al., 2016; Stefan & Van der Merwe, 2008). The absence of a transition policy is problematic in that many studies have shown that poorly enacted transition processes from paediatric to adult care (especially in the case of chronic health conditions) can worsen health outcomes (Busse et al., 2007; Mark, Taing, et al., 2017; Rianthavorn, Ettenger, Malekzadeh, Marik, & Strube, 2004). For example, poor

transitioning to adult care can lead to several consequences for HIV-infected youths, including disruption of care, non-adherence to ART and virological failure (Bailey, Cruz, Songtaweesin, & Puthanakit, 2017; Maskew et al., 2016; Sohn, Vreeman, & Judd, 2017; Tepper et al., 2017). Qualitative studies from South Africa, Kenya, Nigeria, North America and Europe have explored the experiences of HIV-infected adolescents transitioning into adult services from the perspectives of the healthcare workers who provide healthcare to HIV-infected adolescents (Lam, Fidler, & Foster, 2017; Mark, Taing et al., 2017). These studies all elaborate on the lack of adequate standardized protocols, which makes it difficult to determine transition readiness. Furthermore, these studies identify barriers to transition, namely attachment, mental illness, substance abuse, stigma, lack of communication between healthcare providers, negative perception of adult clinics and resource constraints (Hart et al., 2019; Straub & Tanner, 2018). In these studies, healthcare providers offer suggestions with regard to facilitators of transition, and these include the implementation of youth-friendly facilities, a multidisciplinary programme and trained staff (Judd & Davies, 2018). However, the above findings are restricted by small sample sizes and do not include the perspectives of healthcare professionals currently working with youths who have already transitioned into adult care. Ideally, exploring the perspectives of youths themselves would add to our understanding of the factors complicating or enhancing the transition process. However, research among youths in South Africa, especially for vulnerable groups such as this, is challenged by poor parental availability to provide consent for research purposes (Woollett, Peter, Cluver & Brahmbhatt, 2017).

To date, only a few studies have been conducted in South Africa on this topic. This study, therefore, aimed to explore the barriers to and the facilitators of the transition to adult HIV care among HIV-infected youth in the Western Cape from the perspectives healthcare providers who provide paediatric and adult HIV healthcare.

1.2 RESEARCH QUESTIONS

The study was guided by the following research questions:

- How do healthcare providers who offer paediatric and adult HIV services conceptualize and understand transition of care among HIV-infected youth?
- What are the barriers to the transition to adult care among HIV-infected youths from the perspectives of healthcare providers who offer paediatric and adult HIV healthcare?
- What are the facilitators of the transition to adult care among HIV-infected youth from the perspectives of healthcare providers who offer paediatric and adult HIV healthcare?
- In what ways, if any, does the clinic environment in which paediatric and adult healthcare services are provided act as barriers to or facilitators of transition?

1.3 AIM

The aim of the study was to understand the barriers to and facilitators of transition to adult care among HIV-infected youth from the perspectives of the healthcare workers who provide paediatric and adult healthcare services to HIV-infected youth.

1.4 OBJECTIVES

The objectives of the study were:

- to explore the experiences of doctors, nurses, counsellors, pharmacists and support staff who provide paediatric and adult HIV services regarding youth transition and readiness to transition to adult HIV care;
- to identify the barriers to successful transition to adult HIV care;
- to identify the facilitators of successful transition to adult HIV care;

- to observe and document HIV paediatric and adult services at an infectious diseases clinic (from here onwards referred to as Clinic 1) and hospital (from here onwards referred to as Clinic 2) to account for contextual factors that may play a role in transition.

1.5 DEFINITION OF KEY TERMS

Barriers: The circumstances or obstacles that prevent progress (English Oxford Living Dictionaries, 2017, n.p).

Chronic illness: A disease or condition that has one of the following characteristics: is permanent; leaves residual disability; is caused by non-reversible pathological alteration; requires special training of the patient for rehabilitation; or may be expected to require a long period of supervision, observation and care (Goodman, Posner, Huang, Parekh & Koh, 2013).

Facilitators: "To make easier; something that increases the ease with which a function or action is carried out" (English Oxford Living Dictionaries, 2017, n.p).

Transfer to care: "An event or series of events through which adolescents and young adults with chronic physical and medical conditions move their care from a paediatric to an adult healthcare environment" (Knauth, Verstappen, Reiss & Webb, 2006, Pages 619–629).

Transition of care: A "purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented-care systems" (Blum et al., 1993, p 570).

Transition readiness: Transition readiness is defined as "the capacity of the adolescent and those in his or her primary medical system of support (family and medical providers) to prepare for, begin, continue and finish the transition process" (Schwartz, Tuchman, Hobbie, & Ginsburg, 2011; p. 885).

1.6 OVERVIEW OF THE CHAPTERS

Chapter 2 provides an overview of the current literature on the background to adolescence as a developmental stage; chronic illness and adolescence; adolescence and HIV; healthcare transition from paediatric to adult care; barriers to the transition to from paediatric to adult care; and facilitators of the transition from paediatric to adult care.

Chapter 3 gives an overview of the theory that underpins this study. These theories provide a lens through which to organize and understand the findings of this study. This chapter discusses transition theory (Meleis, 2010), as well as Bronfenbrenner's (1979) ecological systems theory (EST).

Chapter 4 describes the methodology of the present study, including the research design, participant selection, and the data collection procedure, which includes: the semi-structured interviews with participants and the naturalistic observation of both healthcare facilities. I also outline the qualitative data analysis methods used, after which I discuss the issue of trustworthiness in qualitative analysis and the relevant ethical considerations.

Chapter 5 documents the demographic information of the study participants and the results of observation data. This includes a discussion of findings of the qualitative thematic analysis with reference to the four main themes identified in the data and the 10 subthemes. The discussion is aided by the use of illustrative quotations.

Chapter 6 discusses the study findings by examining the barriers and facilitators to transition in relation to the relevant literature. I further present the study in terms of the four study objectives stated in Chapter 1 and presents the limitations of the present study. The chapter concludes with recommendations for future work.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides an overview of the relevant literature on adolescence as a developmental stage; chronic illness and adolescence; adolescence and HIV; healthcare transition from paediatric to adult care; barriers to the transition from paediatric to adult care and facilitators of transition from paediatric to adult care**.** The literature was selected by searching the following databases: PubMed, EBSCOhost, Web of Science, Google Scholar and Science Direct. In each of these database searches, I used a combination of the following terms and phrases: (i) (barriers or facilitators) and (HIV/AIDS or HIV care or care transition or transition success or care); (ii) and (children or youth or adolescent or adolescent health); (iii) and (adults' barriers and care and children and adults). Based on the articles found, I categorized the literature into the follow categories: adolescence as a developmental stage; chronic illness and adolescence; adolescence and HIV; transition from paediatric to adult care; barriers to the transition to adult care; and facilitators of the transition to adult care**.**

2.2 ADOLESCENCE AS A DEVELOPMENTAL STAGE

In humans, adolescence begins with the onset of puberty, at which time several biological and psychosocial developments are observed (Graber, Brooks-Gunn & Peterson, 2016; Steinberg, 2014). It is a period of physical growth that leads to reproductive capability and it starts with various changes, including body height, body composition, hormonal changes, and metabolic changes (Graber et al., 2016; Gibbons & Poelker, 2019). Adolescents girls start their growth spurt around 11 years and reach mature stature at 15. Boys' growth spurt starts at 13 years and reaching mature stature around 17 years (Kail et al., 2019; Mendle, Dorn, Beltz, & Carter, 2019). During puberty, the adolescent brain and neural circuitry reaches maturation.

However, the rewards and pleasure-seeking brain systems become more mature than the system that controls behaviour (Goddings, Beltz, Peper, Crone & Braams , 2019). Consequently, while adolescents may know that some of their behaviours at this age may involve several risks, the anticipated rewards and pleasure associated with risky behaviour may overtake their ability to suppress their desire to engage in such activity (Sturman & Moghaddam, 2012). Adolescence is thus, developmentally, a period in life associated with reward- and pleasure-seeking behaviour that may result in risk-taking behaviour.

Adolescence is also a period of maturation. The maturation process often includes intense emotions, sensation-seeking behaviour, risk-taking and the desire to be like peers (Crocetti, 2017; Graber et al., 2016). As mentioned earlier, adolescence is often characterized by high levels of substance abuse, unprotected sex, and sex with multiple partners (Toska et al., 2017). During the developmental transition from early adolescence between 10 and 14 years to late adolescence between 15 and 24 years, adolescents go from concrete thinking towards abstract thinking and develop a sense of social autonomy (Christie & Viner, 2009). Social maturity develops and continues through to young adulthood where relationships with friends become more important and parents remain an essential source of support (Oris et al., 2015). As such, adolescence is a time when adolescents strive to achieve independence and to separate from their parents (Christie &Viner, 2005; Kail et al, 2019).

Biological, cognitive and social changes stimulate adolescents to think and reflect on the kind of individual they want to be (Crocetti, 2017). Adolescence is also known as a phase of developmental conflict between identity formation and role confusion (Erikson,1968). Despite the fact that adolescents experience various changes that lead to role confusion, most adolescents develop a sense of identity that allows them to fit in with society (Kail et al., 2019). Pubertal changes also affect adolescents' psychological functioning so that they become increasingly with about their appearance and experience mood shifts more often (Gibbons & Poelker, 2019;

Mendle et al., 2019). This process of developing autonomy is important for adolescents to achieve self-efficacy and independence (Sattoe et al., 2014).

While healthy, functioning adolescents with caring support can struggle to resolve developmental crises, those with a chronic health condition might be limited and unable to strive towards autonomy (Sawyer et al. 2007; Suris, Michaud &Viner, 2004). As mentioned earlier, adolescence is a time to explore and to take risks to a certain extent, which is a natural process. However, for youth with a chronic health condition, it is vital to have a good understanding of health-promoting behaviour and what can be harmful to their health (Sable, et al., 2011). It is important that HCPs discuss this information with adolescents living with a chronic illness, like HIV, during the transition period to adult care (Reid, et al., 2008). Adolescence specifically in South Africa and Africa is different from adolescence in the Western world given the interplay of socio-political, economic and cultural factors. However, an in-depth review of the literature pertaining to the role that these factors play in the developmental stage is beyond the scope of this thesis.

2.3 CHRONIC ILLNESS AND ADOLESCENCE

Chronic illness in children or adolescents refers to a health problem that lasts three months or more, affects the adolescent's normal activities, and requires frequent hospitalizations, home healthcare, and/or extensive medical care (Mokkink, van der Lee, Grootenhuis, Offringa, & Heymans, 2008). Chronic illness is often characterized by a prolonged duration of the disease, a lack of curability and lifelong treatment (Stanton, Revenson, Tennen, 2007). Over recent decades, the number of children living with a chronic illness has increased significantly, with an estimated 12% of young people aged 10–19 years having a long-term health condition (DOH, 2012; Kirk & Hinton, 2019; Leeman et al., 2016). Evidence shows that chronic illness can affect adolescent development by hindering their ability to form self-identity, self-image and self-esteem (Flocco et al., 2017). Additionally, a chronic illness may delay growth, puberty and

sometimes prevent autonomy (Suris et al., 2004). Youths living with a chronic illness carry an additional burden causing a significant amount of stress. This is associated with risk for emotional and behavioural problems and interferes with adherence to ART treatment, including disengagement from care, non-compliance to medication and failure to achieve viral suppression (Compas, Jaser, Dunn, & Rodriguez, 2012, Guell, 2007; Heaton, Raisanen & Salinas, 2016).

2.4 HIV IN ADOLESCENTS

2.4.1 HIV in adolescents: Globally

The population of youths living with HIV comprises behaviourally and vertically infected adolescents. The success of antiretroviral therapy (ART) has changed the epidemic markedly; firstly, through reductions in mother-to-child transmission and secondly through paediatric ART, which has resulted in increasing numbers of children surviving into adolescence (Rydström, Eriksson & Berlin, 2019; Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) Global Cohort Collaboration, Slogrove, Schomaker et al., 2018; Straub & Tanner, 2018). Despite advancements in ART, the mortality rate among youths aged 15–19 years is increasing (UNAIDS, 2016; Slogrove et al., 2017).

The high mortality rate among these youths shows that there are serious gaps in the HIV care cascade, including low rates of retention in care, and complex challenges with adherence to ART (Lowenthal et al., 2014; Wood, Dowshen & Lowenthal, 2015). It is clear that optimal adherence to ART remains a critical challenge for youths living with HIV around the globe (Okawa et al., 2018).

2.4.2 HIV in adolescents in South Africa

South Africa has the largest ART programme in the world, with an estimated 3.7 million people having initiated ART by the end of 2016 (South African National AIDS Council Trust (SANACT), 2017). However, adolescents are not benefitting proportionately from the ART

rollout (Hodes, Cluver et al., 2018). First-line, second-line and third-line treatment is available in South Africa. First- and second-line treatment are available as part of routine HIV care and intervention for virological failure and drug resistance. However, third-line treatment is more difficult to access and usually requires the input of an infectious diseases specialist (South African National Department of Health (DOH), 2012). Low adherence to ART and retention in care rates are strongly associated with resistance to available antiretroviral therapies, including second-line treatment when it is available (Schramm et al., 2016; Toska et al., 2017). Limited access to second-and third-line antiretroviral treatment means HIV-positive youths are at risk of running out of treatment options or infecting others with resistant strains of the virus (Fairlie, Sipambo, Fick & Moultrie, 2014; Toska et al., 2017).

In South Africa, youths bear a disproportionate burden of the HIV epidemic because of their exposure to various vulnerabilities (Toska, et al., 2017). These vulnerabilities include cognitive and mental health issues (Lowenthal et al., 2014; Sherr, Croome, Parra Castaneda, Bradsha & Herrero Romero, 2014), family-related challenges (Amzel et al., 2013; Wiener & Battles, 2006), poverty (Busza, Besana, Mapunda, Oliveras,2013; Mellins, et al., 2013) and violence (Cluver et al., 2018). The above vulnerabilities are increased by the lack of basic resources such as food, water, sanitation, inadequate infrastructure and poor access to healthcare services (Hodes, Cluver et al., 2018., Shisana et al., 2008). Further susceptibilities arise for young key populations such as young men who have sex with men, transgender people, young sex workers and those who inject drugs (Bekker, Johnson, Wallace & Hosek, 2015).

Risky sexual behaviour is another source of vulnerability among youth in general and HIV-infected youth in particular. A few existing studies point out the high rate of unprotected sex among HIV-positive youths (Cataldo et al., 2012; Mergui & Giami, 2011; Toska et al., 2017). For example, Cataldo et al. (2012) found that the rate of unprotected sex among youths living with HIV in sub-Sahara Africa was between 27% and 90%. In a systematic review of 35

studies documenting the prevalence of sexual risk-taking in HIV-positive youths from 13 sub-Saharan African countries, Toska et al. (2017) reported a high prevalence of high-risk sexual practices among youths aged < 19 years. In most of these studies, one third to one -half of the participants reported early sexual debut. Early sexual debut has been linked to reduced protected sex in the general youth population in South Africa (Toska et al., 2017). Adolescent girls reported a higher prevalence of transactional sex, having older sexual partners, and unprotected sex (Toska, Cluver, Boyes, Pantelic & Kuo, 2015); though adolescent boys were more likely to report early sexual activity and multiple sexual partners (Toska et al., 2017).

2.5 THE TRANSITION FROM PAEDIATRIC TO ADULT CARE IN HIV

2.5.1 Definition and goal of transition

The terms transfer and transition have distinct meanings in the context of healthcare. In the context of this study, a transfer refers to the administrative task of moving a patient with a chronic medical condition from child-centred care to adult-centred care within the healthcare system, usually in the form of a referral letter (AAP, 2018). Transition of care is defined as “The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems” (Blum et al., 1993, p 570). The goal of transition as stated by the American Academy of Paediatrics, the Academy of Family Physicians, and the American College of Physicians, is to maximize lifelong functioning and potential through continuous provision of efficient developmentally appropriate healthcare services as an individual moves from adolescence to adulthood (Fair, Sullivan, Dizney, & Stackpole, 2012; Cooley, Sagerman; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians, 2011).

2.5.2 Healthcare transition in the global context

The transition of care involves complex changes in clinics, models of care, and healthcare providers (Dahourou et al., 2017). Globally, the healthcare transition varies between the type of facilities and institutions. Specifically, transition in an integrated healthcare system differs to transition in a separated (child-centred /adult-centred) healthcare system (Judd &Davies, 2018).

- **Transition in an integrated healthcare system**

Transition in an integrated healthcare system is a process where adolescents are transferred to adult care in the same paediatric clinic and are treated by their previous HCPs (AAP, 2018). In an integrated healthcare system, the change from paediatric care to adult care is not noticeable, since setting and HCPs remains unchanged (Judd & Davies, 2018). Transition in integrated healthcare systems is found in LMIC, including countries in Africa and Asia (Mark, Amstrong, et al., 2017; Judd & Davies, 2018).

- **Transition in a separated healthcare system**

Transition in a separated healthcare system involves a change in location of services from the paediatric clinic to the adult care clinic in the same facility, or in a totally new facility, and treatment by an adult HCPs (Tanner et al., 2018). In the separated healthcare system, clinics are most of the time HIV-specific. These systems are found in both HIC and LMIC such as USA, UK, Canada, South Africa, Nigeria (Mark, Amstrong, et al, 2017, Tanner at al., 2018). Integrated and separated healthcare systems have specific clinic days for paediatric patients and specific clinic days for adult patients (Dahourou et al., 2017). In integrated and separated healthcare systems, adolescents who transitioned to adult clinics have to take the responsibility of their own health by accessing care, health education, adhering to their medication and decision making (Hussen et al., 2015).

2.5.3 Healthcare transition in the local context (South Africa)

2.5.3.1 The South African healthcare system

In South Africa, the post-apartheid dispensation has had a pronounced effect on the health of its people and the health policies and services of the present day (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009). During the apartheid era, political, economic, and land restriction policies structured society according to race, gender, and age-based hierarchies, which created an unequal social life and poor access to basic resources for health and health services (Coovadia et al., 2009). For example, low wages, overcrowding, inadequate sanitation, malnutrition, and stress caused the health of the majority of the black population to deteriorate (Packard, 1989). Current livelihoods and family life are still shaped by South Africa's political and economic history (Winchestera & King, 2018). After many years of democracy, there are still marked differences in rates of disease and mortality between races, which reflects racial inequality in accessing good basic household living conditions and other determinants of health (Neely & Ponshunmugam, 2019; Winchestera & King, 2018).

To date, the public health system has been transformed into an integrated, comprehensive national service, but a lack of good leadership and management have led to inadequate implementation of what are often good policies (Coovadia et al., 2009). South Africa's healthcare system is organized according to a spatial hierarchy, where special care is concentrated in urban areas and basic care is dispersed throughout the country (Neely & Ponshunmugam, 2019**)**. The pressures of everyday life and the national healthcare policy are evident when people access care outside of official policy (Coodavia et al., 2009). In South Africa, 75% of the population accesses healthcare through the public system (Neely & Ponshunmugam, 2019). The legacy of social inequalities perpetuates the cycle of poverty and resource constraints in the black communities (Karim et al., 2009). Additionally, the legacy and

damage caused by HIV/AIDS have left South Africa's public healthcare system resource-poor and inadequate for supporting the country (Karim et al., 2009; Mayosi & Benatar 2014).

The South African, health system faces numerous flaws across various domains: treatment, policy, information and services. Given these flaws, the UNAIDS estimates that HIV testing and treatment remains low among adolescents younger than 15 who are living with HIV as they receive different treatment than adults living with HIV (Mark et al., 2018; UNAIDS, 2016). In South Africa particularly, adolescents are generally considered a healthy population. Adolescents are not prioritized by the healthcare system because all causes of mortality are lower for non-HIV infected youths than for other age groups (Mark et al., 2018; Patton et al., 2016). Consequently, national health information systems have not been designed to focus on monitoring youth health (Mark et al., 2018; Slogrove et al., 2017).

2.5.3.2 Transition from paediatric to adult healthcare for youths living with HIV

In South Africa, children who are diagnosed with HIV are often seen by HCPs who offer paediatric healthcare in the paediatric setting. If such an HCP believes that an adolescent should move over to more specialized adult care, the adolescent is transitioned from an HCP who offers paediatric HIV care to an adult HIV HCP at or before the age of 18 years (Stefan & Van der Merwe, 2008). As mentioned earlier, adolescents are either transitioned in an integrated or a separated healthcare system. There is a marked difference between paediatric and adult healthcare settings in terms of clinic settings, resources and practices. In paediatric settings adolescents living with HIV are seen in a general clinic with general patients (patients with different types of disease), while transitioned adolescents are seen in an adult clinic for HIV patients specifically (Tanner et al., 2018). Paediatric clinics also have sufficient resources, including multi-disciplinary clinicians, counsellors, social workers, psychologists available for patients, while adult clinics are in need of these resources or have limited access (Dahourou et al., 2017; Tanner et al., 2018). In terms of practices, paediatric clinic treatment is conducted by

an HCP who is a specialist in paediatric medicine, while the HCPs in adult clinics are typically generalist clinicians who are often not trained in adolescent medicine (Dahourou et al., 2017; Pettitt, Greifinger, Phelps & Bowsky, 2013).

In paediatric settings, the parents of children with chronic conditions (e.g. HIV) facilitate their children's contact with the HCPs. Parents or caregivers attend clinics together with their children; they take responsibility of their children's health by coordinating all aspects of their treatment, including attending appointments and providing medications (Judd & Davies, 2018; Slogrove et al., 2017). When youths reach maturity also known as adolescence, they must be transition to adult care and take responsibility for their own health (Sohn, Bonsuck, Andrade, Ananworanich & Mark, 2019; Mark, Amstrong et al., 2017). As young people prepare to become responsible for their own treatment, parents have to change their role from a manager to a consultant and advocate in order to facilitate their child's transition from dependence to autonomy (Judd & Davies, 2018; Wiener et al., 2011). As stated by Beacham and Deatrick (2013), the development of healthcare autonomy in children is central to the development of self-care management. Healthcare autonomy means that the adolescent must take responsibility for accessing treatment, adhering to medication, making decisions and defining goals (AAP, 2018; Beacham & Deatrick, 2013). HCPs should support the parents and the youths during this process to help the adolescent reach autonomy and to provide expertise when needed (Reiss, 2012).

For individuals diagnosed with a chronic illness in childhood, moving from paediatric to adult settings and practices could negatively affect the access to and efficacy of the healthcare they receive if they are not ready (AAP, 2018). As indicated by the literature, the process of transition is usually flawed because of a lack of proper planning, poor service coordination, lack of resources and gaps in education and training (Bhawra et al., 2016; Dimitropoulo et al., 2019; Patel & O'Hare, 2010). Parents express uncertainty about how to appropriately support their adolescents during transition (Bratt et al., 2017). In addition, adolescents fear the transition as

they feel unprepared, and adult HCPs feel unprepared to receive and treat transitioned adolescents as they lack training in caring for HIV-infected youths (Le Roux et al., 2017; Philbin et al., 2017).

In order to improve transition processes, there should be a pre-transition assessment to measure readiness (Wiener et al., 2011; Philbin et al., 2017); preparation and support for youths and their parents before transition; as well as post-transfer support (Dimitropoulo et al., 2019) and the implementation of transition policies (AAP, 2018). These factors are explained in greater detail in the section that follows.

2.6 BARRIERS TO TRANSITION TO ADULT CARE AMONG HIV-INFECTED YOUTHS

The next section unpacks the multilevel barriers to and facilitators of transition from paediatric to adult care as found in the literature. Guided by Bronfenbrenner's (1979) EST, the multilevel barriers to and facilitators of transition are explored as they pertain to the microsystem, mesosystem, exosystem and macrosystem. I discuss the barriers to transition in each system, followed by the facilitators in each system.

2.6.1 Barriers to transition at the microsystem and mesosystem level

The section below addresses the following: attachment to healthcare providers; the impact of trauma among transitioning adolescents; poor mental health among transitioning adolescents; substance abuse among transitioning adolescents, stigma among transitioning adolescents; and disclosure among transitioning adolescents**.**

2.6.1.1 Attachment to the paediatric healthcare provider

In their study, Dahourou et al. (2017) found that providers of paediatric health services for young people with chronic diseases, including HIV, were keeping their patients in paediatric care for an excessive time period. The providers voiced their worries with regard to the aptitude

of their youth clients to self-manage within the adult healthcare environment. As a result, the attachment constituted an obstacle to a successful transition.

Miles et al. (2004) conducted a study in London and found that three of the seven HIV-infected youths who were interviewed experienced difficulty and delay in transition because of their relationship with their paediatric care providers. In line with the preceding findings, Lam et al. (2017) found strong attachments between adolescents and their paediatric providers and negative perceptions of adult healthcare providers. Strong patient-provider attachments were also observed among youths in South African studies, which indicates that the healthcare providers feared to transfer unprepared adolescents to what they felt was a judgemental, depersonalized and overburdened healthcare environment (Kung et al., 2016, Mark et al., 2018; Sohn et al., 2017).

In a study conducted in Thailand, Bunupuradah et al. (2015) explored the perspectives of perinatally HIV-infected adolescents (PHIVA) who transitioned to adult care. A total of 19 PHIVA aged between 17 and 22 participated in the study. The population of HIV-positive adolescents (PHIVA) voiced their concerns about the unfriendly atmosphere in the adult clinic, the attitude of adult healthcare providers, the new responsibility, and also who/what they will meet and face at the adult clinic. Attachment to paediatric healthcare providers impedes the transition in that it reduces or limits the ability of HIV-infected adolescents to develop self-management skills necessary in the adult clinic. As indicated for adolescents with a chronic health condition, the healthcare transition means that they have to be prepared to leave paediatric healthcare and enter adult healthcare (AAP, 2018). Bridgett, Abrahamson and Ho (2015) argue the importance of holistic person-centred care to facilitate adolescents during this transition. It is important for adolescents to discuss the challenges that they meet in their life as they work to develop self-management (Bridgett et al., 2015).

2.6.1.2 The effect of past trauma on transitioning adolescents

The term trauma refers to extreme stress that overwhelms a person's ability to cope with life (Giller, 1999). Some studies have found that by the time of healthcare transition, most adolescents living with HIV have navigated years of life stressors, including childhood sexual abuse or loss of a caregiver (Cluver, Fincham & Seedat, 2009; Lam et al., 2017). Maturo et al. (2015) found that one third of the youths in a sample of 104 patients that transferred to adult care had experienced childhood sexual abuse.

Furthermore, in a cohort of 59 youths based in the United States (US) who were transferring to adult care, it was found that 61% had lost their mothers and 51% had lost their fathers (Wiener et al., 2011). Previous trauma or stressors may have an additive or interactive effect on the health condition of survivors of trauma if they are confronted with a new traumatic incident (Breslau, Chilcoat, Kessler, & Davis 1999). As such, previous trauma can increase the vulnerability of the survivor and entails a risk of treatment failure.

HIV-infected youth who have experienced childhood stressors may find themselves in a more vulnerable health condition. The transition to adult care can be perceived as a trigger for symptoms of previous trauma and, therefore, prevent their readiness for transition (Ehlers & Clark, 2000).

2.6.1.3 Poor mental health among transitioning adolescents

Generally, poor mental health is perceived as a complicating factor in the transition process in medical care, and HIV-infected youths who experience poor mental health (i.e. left untreated) are at risk of being lost to care or failing to transition (Gilliam et al., 2011; Straub & Tanner, 2018). In a cohort of 90 HIV-infected youths transferring to adult care in a US-based programme, the prevalence of poor mental health was reported to be between 25% and 61% (Bucek et al., 2016; Mellins & Malee, 2013).

In a quantitative study conducted in North America, Ryscavage, Macharia, Patel, Palmeiro, and Tep (2016) found that 53% to 55% of a sample of 50 HIV-infected youths who transferred to adult care experienced poor mental health. In line with the preceding findings, South African studies show that poor mental health such as depression and anxiety often make it difficult for HIV-infected youth in paediatric care to move to the adult clinic (Dahourou et al., 2017; Kung et al., 2016). Studies conducted in other African countries have also identified poor mental health among HIV-infected youth.

In a study conducted in Kenya, Kamau, Kuria, Mathai, Atwoli and Kangethe (2012), found that 49% of the 162 HIV-infected youth had at least one psychiatric diagnosis or suicidality, with anxiety disorders most common (32.3%), followed by depressive disorder (17.8%).

In a cross-sectorial study from Malawi, Kim et al. (2014) found a depression prevalence of 18.9% among 562 HIV-infected youth. Those youths were more likely to be unable to transition successfully as they were already challenged by a mental illness that reduced their ability to cope with a new stressful situation. In another study conducted in Uganda, Musisi and Kinyanda (2009) found that of the 82 HIV-infected youths participating in the study, 51.2% had scores indicating significant psychological distress, 17.1% had attempted suicide in the previous year, 19.5% and 30.5% had previously experienced psychotic symptoms.

Poor mental health among HIV-infected adolescents remains underreported despite evidence of high prevalence (Vreeman, McCoy &Lee, 2017). For example, a survey in five clinics in Johannesburg (South Africa) revealed that, of the 343 HIV-infected youths aged 13–24, 27% were symptomatic for depression, anxiety or PTSD, and 24% indicated signs of suicide (Woollett et al., 2017). The above result provides some insight into the percentage of HIV-infected adolescents who experience symptoms of poor mental health.

It appears that poor mental health increases among HIV-infected youth transitioning to adult care as opposed to those remaining in paediatric care (Ryscavage et al., 2016). The increase may be related to developmental factors, limited support services in adult care or the lack of knowledge on intervening, preventing and improving mental health problems (Okawa et al., 2018; Straub & Tanner, 2018; Vreeman et al., 2017). For example, one study identified the lack of emotional support in adult services as a risk factor for mental distress among one -third of HIV-infected youths who transitioned to adult care (Wiener et al., 2011). A review conducted by Hussen et al. (2015) revealed that healthcare providers and HIV-infected youth who transitioned to adult care pointed out feelings of loss, anxiety caused by increased autonomy, and logistic challenges of navigating the adult healthcare system as barriers to transition. These barriers had a negative effect on the participants' mental and emotional states. Optimal adherence to medication, regular clinic attendance, ownership of medical care, undetectable viral load and a high CD4 count are characteristic of successful transition (Fair, Sullivan & Gatto, 2011). However, HIV-infected youths experiencing mental illness or those challenged with relational and environmental factors may be less likely to have the characteristics of a successful transition (Tanner et al., 2018; Vreeman et al., 2017). All aspects of HIV-prevention and treatment are negatively affected (Straub & Tanner, 2018). Additionally, adult healthcare providers face challenges in managing the care of HIV-infected youths who experienced poor mental health as they are not prepared in advance to address such cases during the transition (Dowshen & D'Angelo, 2011).

2.6.1.4 Substance abuse among transitioning adolescents

In adolescence, youths are exposed to various risks that increase their vulnerability to HIV, and one of these risks is substance abuse. Substance abuse impairs ART adherence, and retention in care and is described as a risk factor for the acquisition of HIV disease (Murphy, Wilson, Durako, Muenz, & Belzer, 2001). A study conducted by Ryscavage et al. (2016)

revealed that substance abuse ranged between 32% and 58% among HIV-infected youth who had been transitioned to adult care.

2.6.1.5 Stigma and transitioning adolescents

Stigma is defined as "the co-occurrence of labelling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised" (Link & Phelan, 2001). HIV/AIDS is regarded as a shameful disease and many people hold negative perceptions about it. For example, McHenry et al. (2017) explored the perspectives of 39 HIV-infected adolescents in care and 53 caregivers about HIV stigma in Kenya. They found that many community members held negative and inaccurate views about HIV, including associating it with immorality and believing in transmission by casual interactions. HIV/AIDS-related stigma is also identified as a risk factor for HIV transmission and a barrier to all aspects of HIV treatment, including HIV testing, enrolment in care, retention in care, adherence to medications and transition (Dlamini et al., 2009; Kalichman & Simbayi, 2003; Tanner et al., 2018; Toska, Cluver, Hodes & Kidia, 2015).

Stigma emerges as a barrier to transition, engagement in adult care, quality of life and it prevents HIV-infected youths from disclosing their status to persons in their social group (Dahourou, 2017; Fair, Allen & Trexler, 2016; Rydström, Wiklander, Navér, Ygge, & Eriksson, 2016; Wiener et al., 2011; Pantelic et al., 2018; Tanner et al., 2018). For example, Vijayan, Benin, Wagner, Romano and Andiman (2009) explored current challenges in a USA paediatric care as well as potential barriers to transition to adult care among 18 HIV-infected youths, 15 parents/guardians and 9 care providers. They found that HIV-related stigma made patients and guardians cautious about meeting new providers. According to Earnshaw and Chaudoir (2009), HIV-positive individuals experience stigma through three mechanisms, namely enacted, anticipated and internalized stigma (Earnshaw & Chaudoir 2009). Enacted stigma refers to experiences of discrimination or having been treated differently due to one's HIV status; anticipated stigma refers to the extent to which HIV-positive people perceive or anticipate

prejudice against them; and internalized stigma occurs when an HIV-positive person internalises negative attitudes associated with HIV and accepts these as applicable to him- or herself (Earnshaw, Smith, Chaudoir, Amico & Copenhaver, 2013; Pantelic, Boyes, Cluver & Meinck, 2017). Adolescents living with HIV experience all three levels of stigma, hindering them from disclosing their HIV status to others (Pantelic et al., 2017).

Meanwhile, not disclosing HIV status can be detrimental to health as it prevents HIV-infected youths from seeking emotional and active support aimed at improving retention in clinical care and adherence outcome (Dahourou et al., 2017). For example, one study by Cluver et al. (2015) has shown that adolescents who have not disclosed their status have three times the likelihood of non-adherence to ART. Similarly, Coetzee, Kagee and Vermeulen (2011) found that non-disclosure of HIV status limited support from friends or family who could encourage PLHIV to attend clinic appointments or remind them to take their medication. PLHIV who do not disclose their status is not able to take medication openly, nor to attend their clinic appointments.

In another study, McHenry et al. (2017) found that among the 39 HIV-infected adolescents receiving care in Kenya, stigma was closely related to a loss of social and economic support, but also included internalized negative feelings about oneself. Participants identified treatment-related effects of stigma, including non-adherence, nondisclosure of status and increased mental health problems.

One can conclude that non-disclosure and stigma hinder the ability to form social networks in the microsystem. Inadequate interactions within the microsystem may result in a cascade of disruption throughout all levels of systems of the ecological model (Bronfenbrenner, 1979). The literature consistently points to trauma, poor mental health, substance abuse, stigma and disclosure as issues that hinder the smooth transition from paediatric to adult care of HIV-infected adolescents. However, there are no concrete measures to address these issues. The

present study sought to identify the potential solutions through the interviews of participants and the naturalistic observations.

2.6.1.6 Disclosure of HIV status among transitioning adolescents

The literature describes four scenarios related to the disclosure of HIV status among adolescents: the first scenario is when caregivers disclose their own HIV-positive status to their children (Rochat, Mkwanazi & Bland, 2013); the second is when parents or healthcare providers inform adolescents living with HIV that they (adolescents) are HIV-positive (Heeren, Jemmott, Sidloyi & Ngwane, 2012); the third is when adolescents living with HIV disclose their status to a third party (Siu, Bakeera-Kitaka, Kennedy, Dhabangi &, Kambugu, 2012) and the fourth is when adolescents' HIV-positive status is disclosed to a third party by their parents, guardians or healthcare providers (Siu et al., 2012). Each of these forms of disclosure can open up avenues for improved adherence, psychosocial support and acceptance of the diagnosis (Midtbø, Shirima, Skovdal & Daniel, 2012; Blasini et al., 2004; Hejoaka, 2009).

For an adolescent, having the ability to decide when and how to disclose their status to significant others may help them feel more empowered and autonomous (Dahourou et al., 2017; Mburu et al., 2014). In that way, disclosure may play a role in facilitating the process of transition from paediatric to adult care. However, disclosure can become detrimental to the health, treatment and healthcare transition of HIV adolescents if proper procedure is not followed. For example, adolescents living with HIV report experiencing anxiety, fear and stigma when disclosing their status (Madhombiro et al., 2019; Toska et al., 2015). Stigma and the perceived lack of acceptance by communities cause adolescents and young adults to refrain from disclosing their status to significant others (Mburu et al., 2014; Tanner et al., 2018, Vreeman et al., 2015). As a result, greater demands are placed on healthcare providers, thus increasing the work pressure. Furthermore, disclosure causes avoidance of treatment centres and reluctance to attend support groups or utilize mobile health (Dahourou et al., 2017; Tanner et al., 2018).

Studies that examine HIV disclosure among young people suggest that disclosure ought to be a process rather than a single event (Lesch, Swartz, Kagee, Moodley, Kafaar, Myer et al., 2007; Wiener et al., 2007). One way of avoiding the negative effect of disclosure might be the completion of disclosure long before sexual activity begins as it may improve adherence and acceptance of the disease (WHO, 2011).

According to the WHO recommendations, the disclosure should occur before 12 years of age and must be applied to each individual context in consideration of the level of insight and maturity (WHO, 2011). In practice, however, disclosure to adolescents living with HIV in sub-Saharan Africa varies widely and is often inconsistent with the WHO recommendations (Mburu et al., 2014. For example, parents living with HIV are often unwilling to disclose their own status to their adolescents, and they delay informing adolescents of the adolescents' HIV infection (Brown et al., 2011). Several studies reveal that the barriers to disclosing adolescents about their HIV-positive status is related to the parents believing their child is not ready or is too young to understand the meaning of an HIV diagnosis (Brown et al., 2011; Heeren et al., 2014; Petersen et al., 2010).

Additionally, the link between HIV and sexuality presents a barrier to disclosure. Research has also shown that sexual and romantic relationships among HIV-infected adolescents are shaped by complex factors, including knowing one's partner's status (Alemayehu, Aregay, Kalayu, & Yebyo, 2014), stigma (Li, et al., 2010; Mburu et al., 2014), medication-taking (Marhefka, Elkington, Dolezal, & Mellins, 2010), desire for love and acceptance (Zamudio-Haas, Mudekunye-Mahaka, Lambdin, & Dunbar, 2012), and progression of HIV disease (Cooper et al., 2007). For example, in one study conducted in the Eastern Cape in South Africa, Toska et al. (2015), interviewed eight hundred and fifty eight HIV-positive adolescents (10–19 years old, 52% female, 68.1% vertically infected) who never initiated antiretroviral treatment. Results indicated that fear of rejection and stigma discouraged HIV-positive adolescents from revealing

their status to their partners as a strategy for negotiating safer sex. Meanwhile, the author discovered that disclosure to and by HIV-positive adolescents was associated with safer sex.

In view of all these challenges, securing a relationship might be perceived as a great achievement and source of support that HIV infected adolescents' may not want to lose. A study conducted in Zambia by Mburu et al. (2014) explored the disclosure of HIV status to adolescents living with HIV, adolescents' disclosure of their status to others, and the impact of both forms of disclosure on adolescents. A total of 53 adolescents aged 10–19 with their parents (n=21) and 24 healthcare providers participated in the study. Findings revealed three main barriers to disclosure of HIV status: local norms that prevented parents from communicating with their children about sexuality; fear of HIV stigma; and an underlying presumption that adolescents would not understand the consequences of an HIV diagnosis on their lives and relationships. Alongside adolescents' barrier to disclosing their HIV status to their sexual partners was related to fear of rejection. At the individual level, some adolescents described being anxious, depressed and blaming themselves after being told they had HIV. At the interpersonal level, disclosure created opportunities for adolescents to access adherence support and other forms of psychosocial support from family members and peers. At the same time, it occasionally strained adolescents' sexual relationships, although it did not always lead to rejection.

Those findings show that most sub-Saharan African countries lack specific guidelines on when to disclose and that is standing as a barrier to a successful transition (Dahourou et al., 2017; Mburu et al., 2014). That in itself constitutes a barrier to transition.

2.6.2 Barrier to transition at the exosystem and macro-system level

2.6.2.1 Adult clinic environment and impact on transitioning adolescents

In their review of differences and commonalities in transition experiences for adolescents with perinatally and behaviourally acquired HIV, Lam et al. (2017) determined that adolescents living with HIV and their guardians perceived adult healthcare providers as unfriendly. Both

adolescents and their guardians held negative perceptions regarding adult healthcare providers in terms of patient load, the expectation of patient autonomy, length and frequency of appointments, clinic setting and patient population (Lam et al., 2017). This finding was in line with Tanner et al. (2018) and Okawa et al. (2018).

Kakkar et al. (2016) conducted post-transition interviews with 25 patients who had transferred at age 18 years from a Montreal-based paediatric HIV programme to adult HIV care. The authors found that the majority of participants would have preferred deferring transition to a later age, and many expressed concerns about adapting to the inflexibility of the adult clinic environment (Kakkar et al., 2016).

2.6.2.2 Lack of standardized policies on transition

Several prominent scholars in the field have noted the absence of standardized policies and tools to support the transition to adult care (Judd & Davies' 2018; Lam et al., 2017; Mark et al., 2018, Sam-Agudu et al,2017). There are also gaps in the healthcare policies that constitute a dilemma, in moving these policies to practice at global, national and local levels (Mark, Taing, et al, 2017). The gaps in the policies include omissions, inconsistencies and constraint of laws in adolescent-centred sexual and reproductive health (SRH) services; mental health; peer to peer services; and family-centred psychosocial care (Lam et al.,2 017; Mark, Taing, et al., 2017; Tepper et al., 2017). As a result, critical services and support that could effectively prepare adolescents for self-management after the transition period are missing from national health strategies. Studies illustrating the above issue are provided below.

Hope et al. (2016) examined post-transitioned HIV-infected youth in the United Kingdom-based Collaborative HIV Paediatric Study (CHIPS). The authors found poorer outcomes, namely non-retention in care, lack of viral suppression and non-adherence to ART among youth transferred to external adult clinics as opposed to youth transferred to adult care in the same facility. Out of 211 youths, 55% of the patients were transferred externally and

demonstrated higher rates of clinic non-attendance and death. South African studies demonstrate the same issue (Dahourou et al., 2017; Mark, Amstrong, et al., 2017; Kung et al., 2016). In another study, Kung et al. (2016) found that the transition process was based on indicators. These indicators include age (ranging from 16 years to 25 years across providers); completion of high school; request to move to adult care; completion of the isiXhosa manhood initiation ritual involving male circumcision; and pregnancy in young female adolescents, regardless of age (Kung et al., 2016). This finding was corroborated by Mark, Amstrong, et al. (2017) who showed that one-quarter of facilities throughout 23 Sub-Saharan countries, including South Africa (82.38%), were challenged by adherence to treatment of HIV-infected youth, reflecting an insufficiently targeted approach for adolescents.

Throughout the above literature, different approaches to transition that are described depict a lack of general consensus with regards to guidelines and policies that should be standardized and adopted. Thus hampering the transition process and promoting delays in servicing the population at risk (HIV-infected youth).

2.6.2.3 Resource constraints for transitioning adolescents

Studies in South Africa show that the necessary comprehensive follow-up after the patient has been transferred is unlikely to occur (Dahourou et al., 2017; Kung et al., 2016). In addition, engagement of adult HIV doctors in processes such as meeting the patients in the adolescents' clinics are unrealistic, and resources for hiring trained staff such as social workers and counsellors to accompany adolescents on their initial adult clinic visits are lacking (Dahourou et al., 2017; Geary, Gómez-Olivé, Kahn, Tollman, & Norris, 2014; Kung et al., 2016).

The above mention barriers impede on the transition of HIV- infected youth by reducing their ability for self-reliance, self-efficacy, and adjustment to the adult care (American Academy of Paediatrics (AAP), 2013; Rapid Response Service (RRS), 2015). For example, HIV-infected

youth who transitioned to adult care are subjected to new changes (timing, appointment, doses of medication, new healthcare provider, new environment and others) (AAP, 2013; Bunupurada et al., 2015). The changes might be very challenging to cope with and might result in consequences such as health complication, drop-out, loss to follow-up, non-adherence to medication and even death.

Exploring the perceptions of adult HIV healthcare professionals regarding the barriers and facilitators that relate to the transition of youth would likely provide a clearer picture of the factors that hamper the smooth transition of HIV-infected adolescents to adult treatment. Few studies have explored the transition to adult service among adolescents living with HIV in Africa (Lam et al., 2017; Mark, Amstrong, et al., 2017; Tepper et al., 2017, Straub & Tanner, 2018), and available literature is predominantly qualitative. In addition, little is known about events after transition and thus, further studies exploring the perceptions of adult and youth HIV healthcare professionals are needed. Throughout the literature, the clinic environment, the lack of standardized policies on transition and resource constraint have been pointed out as the external barriers to transition. These barriers have been highlighted by healthcare providers working with HIV infected youth. This study explores the perspectives of healthcare providers on the issue.

2.7 FACILITATORS OF THE TRANSITION OF HIV-INFECTED YOUTH TO ADULT CARE

The literature on HIV care transition highlights actions that lead to positive outcomes with regard to transition of HIV-infected youth to adult care (AAP, 2018; Cluver et al., 2018; 2015; Straub &Tanner, 2018; Tepper et al., 2017). These actions include the implementation of a youth-friendly, multidisciplinary approach together with consistent integration and communication between healthcare providers who offer paediatric and adult care. As such, the voices of adolescents living with HIV should be included in the development and evaluation of

healthcare transition protocols. Involvement of all key stakeholders is, therefore, necessary to formulate implementable healthcare transition policies for HIV-infected adolescent youth.

2.7.1 Youth-friendly services for transitioning adolescents at the exosystem and macrosystem

Youth-friendly services have been identified as a leading factor to a positive outcome on transition (Straub &Tanner, 2018). Bundock et al. (2011) and Maturo et al. (2015) conducted studies in the United Kingdom and found that the transition process was highly successful in healthcare facilities that provided multidisciplinary, youth-friendly services with shared paediatric and adult HIV care.

The formation of youth support groups as facilitators of transition was also suggested in South African studies (Dahourou et al., 2017; Geary et al., 2014; Kung et al., 2016; Tepper et al., 2017). Indeed, in a sample of 50 healthcare professionals in South Africa, respondents agreed that the formation of adolescent support groups in adult care clinics, in addition to a later transition age, would improve the transition process (Kung et al., 2016). These findings are in keeping with a study conducted in Khayelitsha (South Africa) by Henwood et al. (2016) in which retention in care was high among HIV-infected youth that attended youth clubs and even higher amongst those who were stable on ART.

Sharma, Willen, Garcia and Sharma (2014), explored the opinions of HIV- infected youth and their parents on the preparedness to transition to adult care in Miami. Fifteen HIV- infected youths aged 15–24 and 8 parents not related to the youth were interviewed. The following suggestions were provided: an early process of transition with specific guidelines and knowledge about HIV healthcare enabling self-management of health; a request for more autonomy and enhancement of the independency while in paediatric care; having adult providers learn skills specific to the treatment of youth; improve communication between all parties (patients, parents/ guardians, paediatric and adult healthcare providers) involved in the transition process; the

preparation of youth for the expected changes in atmosphere and behaviours at adult settings, besides providing a peer support to ease discomfort in adult settings.

In a qualitative study conducted in the USA, Valenzuela, Buchanan, Radcliffe, Ambrose, Hawkins and Rudy (2009) explored the perspective of 10 HIV- infected youth with regards to facilitators of transition. Findings revealed that participants experienced adolescent care providers as an important source of support. Even though they felt anxiety about transition, they were able to describe significant positive changes associated with adult HIV care. HIV-infected youth recommended a clearer transition process, with collaborative planning among youth and health-care teams, more time to prepare for the transition, more options for individualized services, and more help coordinating and linking services, especially since adult services were described as fragmented and difficult to access.

In another study, Fair et al. (2012) explored the expectations of both HIV infected youth and their guardians on the pending transition to adult care. The authors interviewed 40 HIV-infected youth (aged 17.3 years) receiving care in a paediatric clinic in the USA and 17 guardians. It was found that many adolescents had difficulty articulating expectations of their transition to an adult clinic. Others looked forward to increased responsibility and control, while some expressed concerns over leaving their current providers and having to establish new relationships. Most guardians viewed the transition to adult care as a tool to facilitate maturity. Several guardians indicated that they had not discussed the transition with their child and were waiting for their child to initiate a conversation about it, while others suggested that providers should approach the transition from a developmental perspective that is tailored to the specific needs and strengths of each adolescent.

In Thailand, Hansudewechakul et al. (2015) evaluated transition outcomes of 67 adolescents who prepared for transition through a two-day camp. The youth were introduced to the adult care team in groups of 10–15, before transitioning to the adult HIV clinic in the same

hospital. After five years of post-transition, the majority of youth remained in follow-up care with good virological outcomes. It was found that having adolescents visit adult services with the paediatric team facilitated positive peer interactions that provided resilience against poor drug compliance, alcohol use, difficult family relationships as well as other life issues. This is line with Bundock, et al. (2011), findings where several youths who had transitioned from a paediatric clinic to adolescent care appreciated the increased responsibility and getting ‘‘treated like an adult”.

Although studies were from different setting, participants (HIV-infected youth) voices were unanimous on the positive outcome of their health after transition. Thus emphasizing that well-planned transition allows youth to optimize their health, to independently manage their disease and to assume adult roles and functioning (Maturo et al., 2015; Tepper et al., 2017). All these studies were limited by the small sample size and participants were mostly female.

2.7.2 Multi-disciplinary approach in the services

There is some evidence to suggest that a multi-disciplinary approach may facilitate the transition process. For example, in a study conducted in Thailand, Lolekha et al. (2017) implemented a Happy Teen (HT) programme to prepare HIV-infected youth for the transition to adult HIV care. The programme was structured to cover aspects of health knowledge, coping skills, sexual risk reduction and life goals using individual and group activity sessions. Group sessions included youth, adult and paediatric healthcare providers. Findings revealed a marked improvement in care services and in the transition process. Other improved outcomes included increased communication within families and between healthcare providers and youth, and increased treatment uptake and adherence. Further, the number of youths receiving ART increased from 45% at baseline to 82% at 12 months and 95% at 18 months. An increase in knowledge useful for a successful transition from paediatric to adult HIV care was also reported

(Loletha et al., 2017). The benefits of this approach are echoed in other studies (Dahourou et al., 2017; Lam et al., 2017; Mark, Amstrong, et al., 2017).

2.7.3 Communication between transitioning adolescents and adults HCPs

South African studies suggest improved communication and the formation of youth support groups as facilitators of transition in the South African context (Dahourou et al., 2017; Geary et al., 2014; Kung et al., 2016; Tepper et al., 2017).

Global studies show that existing protocols for successful transitions are framed within the Western context (Kung et al., 2016; Mark, Taing, et al., 2017; Tepper et al., 2017). As a result, the protocols may not be suitable for application in all areas, for example, in resource-limited settings such as Africa and Asia. Thus, there is a need for protocols that are inclusive of other cultures and contextual realities.

The above section has presented evidence of successful transition that is aligned to the recommendation provided by the American Academy of Pediatrics (AAP, 2018), which resumed successful transition into four steps: (1) development of written policies to guide transition; (2) joint creation of a transition plan by youth, family and providers; (3) planned facilitation of youths' connection to adult clinics as transition is initiated; and (4) communication between adolescent and adult clinics during the transition process for quality assurance review (Committee on Pediatric AIDS, 2013).

2.8 CHAPTER SUMMARY

In this chapter I have expanded on adolescence as a developmental stage, chronic illness and adolescence, HIV in adolescents and the transition from paediatric to adult care in HIV adolescents**.** I discussed each of these within the global and South African contexts. Further, I discussed barriers and facilitators to transition to adult care among HIV-infected youth. The literature shows that attachment to healthcare provider, trauma, mental ill-health, substance

abuse, stigma disclosure, adult clinic environment, lack of standardized policies on transition and resources constraints constitute a barrier to transition of HIV infected youth. Alongside, the literature shows that youth-friendly services for transitioning adolescent, multi-disciplinary approach and communication between transitioning adolescents and adult HCPs can facilitate the transition from paediatric to adult care of HIV-infected adolescents. Despite the existence of written protocols on transition, there is a gap in its implementation; alongside there is a lack of standardized policies to inform the process of transition in both global and South African contexts. To address the problem faced by this transitioning age group and ensure safe transitioning to adulthood for all youths living with HIV, programming that is responsive to their vulnerabilities should consider.

2.9 RATIONALE

As demonstrated in the literature overview, managing the process of transitioning youth from paediatric to adult care is particularly challenging in many resource-limited settings, and little is known about adolescent continuity in adult care (Dahourou et al., 2017). A lack of continued engagement with young people can reduce trust in health services, lead to poor clinical outcomes and negatively affect society as a whole.

The proposed study could aid in the identification of specific factors that hamper transition among adolescents in the South African context. Healthcare professionals working with HIV infected youth are likely to provide useful and practical suggestions regarding factors or techniques that may be more appropriate than a review of the previous literature and thus address the gap in the literature. These insights from healthcare providers may lead to improvement of the health conditions of HIV infected youth, reduce the mortality rate and thus, decrease the cost of HIV/AIDS treatment at both individual and country levels. Although Kung et al. (2016) have described the barriers, facilitators and model components in regard to transition in the Western Cape, the findings are limited by the small sample size (n=7) of

physicians and counsellors. Further, there is a notable absence of the perspectives of the healthcare providers that work with youth who have already transitioned to adult HIV care. In addition, interviews and surveys were the only instruments used for data collection. Further, there was no direct observation of the clinic environments (paediatric and adult clinics often run separately) which may provide insight into the contextual factors that may influence transition.

The study therefore includes a multi-stakeholder (doctors, nurses, counsellors, pharmacists, support staff) perspective, as well as observation of paediatric and adult clinics to better understand the factors that influence transition from paediatric to adult HIV care.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 INTRODUCTION

In this study, I draw on two theoretical frameworks through which to conceptualize, organize and understand the findings from this research. Firstly, I draw on Meleis' Theory of Transition (2010) guided by the discussion of the transition process from paediatric care to adult care. Secondly, I draw on Bronfenbrenner's (1979), EST. Bronfenbrenner's (1979) EST was particularly useful in organising the literature and findings pertaining to the barriers to and facilitators of transition among HIV-infected youths.

3.1.1 Meleis' Theory of Transition

In his Theory of Transition, Meleis posits that transitions are the normal changes and processes that everyone will experience over the course of their life (Meleis, 2010). Examples of transitions that may cause patients to be vulnerable include: illness experiences such as diagnosis, surgical procedures, rehabilitation and recovery; development and lifespan transition such as pregnancy, menopause, aging and then; and socio-cultural transitions such as migration, retirement and family caregiving (Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994). For an individual, different changes in health status might result in improved health and well-being or expose the patient to risks for illness, and this can provoke a process of change and transition. These transitions are experienced individually, and those who undergo a transition are often vulnerable and might experience stress that can affect their health (Kaiser, Kaiser & Barry, 2009; Meleis, 2010). By identifying and understanding the meanings and conditions of the transition, healthcare providers (HCPs) can facilitate and reduce barriers, which can result in improved quality of care for the patient and family and ensure healthier transitions (Geary & Schumacher, 2012; Knaulth et al., 2006; Meleis, 2010). A successful transition is characterized

by both process and outcome indicators. Because a transition is a process that develops over time, it allows HCPs to identify the process indicators (e.g. being involved in the care and coping) that can lead the patient towards health or vulnerability. The outcome indicators in the transition theory are mastery of new skills and fluid integration of the transitioned individual (Meleis, 2010).

Often an individual experiences multiple transitions at the same time (Fairlie et al., 2014; Geary & Schumacher, 2012). Youths can simultaneously experience natural developmental milestones (such as leaving childhood and entering adolescence), situational transitions (such as moving from one grade to the next or changing schools), health/illness transitions (such as receiving a new diagnosis or requiring medical intervention), and organisational transitions (such as changing healthcare setting and acquiring new caregivers) (Fairlie et al., 2014; Meleis, 2010). To understand youth's experiences during the different transitions, it is necessary to identify personal and environmental conditions that act as facilitators or barriers to a healthy transition or outcome (Geary & Schumacher, 2012; Meleis, 2010). Meleis describes three conditions: Personal conditions, meaning the need for preparation and knowledge about the change; community conditions, including family support and relevant information from trusted HCPs; and societal conditions, such as when the individual experiences the transition as stigmatising (Meleis, 2010).

As described above, Meleis' transition theory was drawn upon to explore the multiple transitions that HIV-infected adolescents undergo and how these transitions are interconnected as they take place at the same period (developmental stage). Further, the theory helps to understand that undergoing multiple transitions can be challenging for HIV-adolescents as it makes them be more vulnerable. However, supporting and preparing adolescents before and after transition is beneficial.

3.1.2 Bronfenbrenner's Ecological Systems Theory

In order to understand the barriers and facilitators relating to the transition of HIV infected youth to adult care, I used Bronfenbrenner's EST. Bronfenbrenner viewed human development as taking place within a series of social and cultural systems at different levels (Claiborne & Drewery, 2010; Feeney et al., 2010). At the centre of this hierarchy of interrelated systems is the individual, with systems influencing both one another and the individual. There are five "levels" in Bronfenbrenner's framework: the microsystem, mesosystem, exosystem, macrosystem, and finally the chronosystem. Bronfenbrenner's framework is relevant as a way to contextually situate the understanding of the barriers and facilitators that exist in the transition to adult care from the perspectives of healthcare providers working with HIV infected youth.

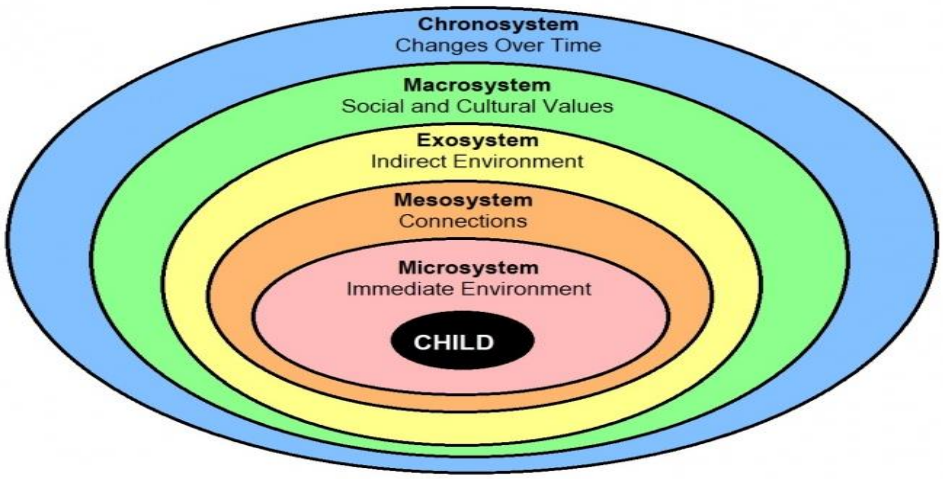

Figure 3.1: Bronfenbrenner's Ecological System Theory

EST focuses on the quality and context of a child's environment (Bronfenbrenner, 1979). According to EST, individuals interact with different environments throughout their lifespan, and these environments are likely to influence their behaviour to various degrees (Bronfenbrenner, 1979).

The microsystem (i) is the primary level of the direct interaction affecting the child development and the immediate setting within which the child has had the most direct interactions with immediate people (example parents, caregivers and healthcare providers). Structures in the microsystem include family, school, neighbourhood, or childcare environments. The microsystem is defined as "a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features, and containing other persons with distinctive characteristics of temperament, personality and systems of belief " (Bronfenbrenner, 1992, p. 227). In this study, the mecrosystem is the healthcare providers, the caregivers and the peers in the clinic with whom the adolescent is in direct interaction. The second level is the mesosystem (ii) and includes interactions between members of the mesosystem: for example, the connection between the adolescent's teachers, parents, church and neighbourhood. This level involves the relationships and processes that occur between two or many settings comprising the individual (HIV adolescent). Bronfenbrenner connects the mesosystem to "a system of microsystems" (Bronfenbrenner, 1992, p. 227). The exosystem (iii) represents the third level and includes the processes that occur between two or more settings, at least one of which does not include the developing individual (HIV infected adolescent) directly. The exosystem consists of broad social systems including hospitals, organisations, workplaces, communities in which the individual does not actively participate, but he/she (HIV-infected adolescent) is indirectly influenced by those different layers. The macrosystem (iv) includes cultural characteristics, political upheaval, or economic disruption, all of which can impact an individual. In this study, the macrosystem represents the lack of policies on transition that have a direct influence on the clinics process and an indirect impact on the health of the adolescent. Finally, the chronosystem (v) refers to the influence of time and how it relates to the child's environment. These can be external influences, such as the death of a close family member or internal influences such as puberty

(Bronfenbrenner, 1989). Each system has either a direct or indirect influence on the individual (Bronfenbrenner, 1986). For example, psychological, physical, and genetic intrapersonal factors in the microsystem can have a direct influence on the HIV- infected youth's well-being and result in the non- adherence to medication. In addition, others systems with whom the HIV-infected youth is in a bi-directional relationship (parents, healthcare professionals working with HIV infected youth, school teachers, neighbours and peers) might positively or negatively influence the transition process of the HIV infected youth. Socio-economic factors such as violence, poverty unemployment might negatively impact the transition. The EST offers a holistic approach to identifying factors that are perceived as barriers and facilitators with regard to the transition to adult care across multiple levels.

While the EST consists of five environments or five systems, this study focuses on four levels namely the microsystem, the mesosystem, the exosystem and the macrosystem. In this study, participants comprised the healthcare professionals (doctors, nurses, counsellors, pharmacists, two administrative clerks and one HIV data capturer) with whom the adolescents had direct contact during clinic visits. In this study HIV- infected youth, healthcare providers, caregivers and peers are situated in the microsystem level; at this level there is a proximal interaction influencing the adolescent. The mesosystem in this study comprises the healthcare providers, the HIV-peers, caregivers' close relative friends and peers in the community with whom the adolescent has a bi-directional interaction and there is mutual influence between the different parts. The exosystem in this study include social factors example poverty; these factors have an indirect influence on the adolescent (e.g adolescent might be unable to attend clinic appointment lack of money). The macrosystem in the study represents factors that indirect influence on the child health for example laws, policy and economic factors.

3.2 CHAPTER SUMMARY

Transition Theory and EST inform the present study, with the two theories complementing each other. Transition Theory describes the multiple transitions occurring at the same period of development stage and how these transitions are interlinked. The EST allows for identification of factors impacting on the transition process and individual who is transitioning by describing how it takes place. Meleis' and Bronfenbrenner theories complement each other in that, the transition process takes place in a system with different layers including family, friends, significant others, believes, laws, policies. These layers' exercise direct and indirect influence on the transitioning adolescent and have the capacity to positively or negatively altered the healthcare care transition.

CHAPTER 4

METHODOLOGY

4.1 RESEARCH DESIGN

This qualitative study was framed following an interpretivist and social constructivist worldview (Creswell, 2013; Denzin & Lincoln, 1994**).** A qualitative approach was suitable for this study because it allowed for a better understanding of the barriers and facilitators relating to the transition of HIV-infected adolescent's to adult care from the perspectives of doctors, nurses, pharmacists and counsellors and support staff.

4.1.1 Philosophical positioning

Philosophical assumptions are abstract ideas and beliefs that inform valid research (Creswell, 2013). These assumptions are categorized into ontology (nature of the reality), epistemology (knowledge and how knowledge is claimed), axiology (role of values in research) and methodology (Creswell, 2013; Lincoln & Guba,1986). The proposed qualitative study was framed following an interpretive and social constructivist worldview. Such an assumption was appropriate for this study because it helped to uncover participants' subjective experiences of the external world in a socially constructed manner (Guba & Lincoln, 1981). In a qualitative study, the researcher is a participant-observer who engages in the activities and discerns the meanings of actions as they are articulated within specific social contexts (Carr & Kemmis, 1986). In qualitative research, it is argued that the researchers' views can bias the research design by influencing the data collection. Some participants' may be previously influenced, and this can affect the outcome of the data (Christensen, Johnson, & Turner, 2011). Critical reflection and reflexivity were built into this study to ensure that the research is learning-oriented and that previously held assumptions or ideas of the researcher are challenged. The present study was grounded in EST. As noted in chapter 1 the EST posits that individuals interact with different

systems throughout their lifespan and each system has either a direct or indirect influence on the individual (Bronfenbrenner, 1986). An interpretive social constructivist worldview has helped to uncover the healthcare professionals' (counsellors, pharmacists, doctors, nurses) realities with regard to the barriers and facilitators in transition into adult care amongst HIV infected adolescents. Through semi-structured interviews, I was able to observe and discern the meanings of the healthcare professionals' experiences in their context. The focus was therefore not only on describing daily activities or interaction in the healthcare setting, but also how the individual (adolescents living with HIV), the family, the healthcare and the society context influenced these experiences. Exploring the experiences throughout the four levels: microsystem (i), mesosystem (ii), exosystem (iii) and macro-system (iv) served to provide a clear understanding of the barriers and facilitators of transition amongst HIV infected adolescents.

4.1.2 Study setting

The study took place at two Infectious Diseases Clinics in the Boland region of the Western Cape. Clinic 1 was based in Somerset West, which is situated outside Cape Town, South Africa. Clinic 2, was located close to Stellenbosch University campus. Both healthcare facilities are among the two largest sites providing paediatric and adult HIV treatment services in the Western Cape. In consultation with the clinic manager at Clinic 1 and the attending clinician at Clinic 2, I learned that adolescents and adults attended the clinic on separate days. At Clinic 2, adolescents were seen on Thursdays and adults usually every other day of the week. While at Clinic 1, adolescents were seen on Mondays and adults usually every other day of the week. Since the days for adolescent and adults differed, I included an observational phase to this study.

Clinic 1

The Infectious Disease Clinic (IDC) at Clinic1 was a recruitment and data collection site of the present study. Clinic1 was located in Somerset West, outside of Cape Town. This

health district services the towns of Somerset West, Strand, Gordon's Bay, and other smaller areas. Through the IDC, an outpatient section of the hospital, Clinic1 provides a separated (as opposed to integrated) ART service for both paediatric and adult patients. The paediatric clinic was situated in the upper area of the building where general patients were seen. Consultation for paediatric HIV patients took place on a Thursday, during which young adolescents and children accompanied by their caregivers were seen by the paediatric doctors. The adult's HIV Clinic was situated in the IDC section (ground floor) of the building. Consultations for adult's HIV patients and transitioned HIV adolescents took place every other day of the week. Both adults and adolescent's HIV patients were seen by sisters or adult clinic doctors. The interview sessions of the present study took place in the Pharmacy counselling room, located on the ground floor of the building and the paediatric doctor consultation room situated at the upper side of the building.

Clinic 2

The IDC (Infectious Disease Clinic) at Clinic 2 was the second site for the data collection of the present study. The Clinic is situated in Stellenbosch and services the Stellenbosch area as well as Kayamandi, Klapmuts and other smaller areas. The IDC clinic occupies one space and offers integrated ART services for paediatric and adult HIV patients. The paediatric patients were seen on a Monday and the adult patients were seen every other day in the week. Both paediatric and adult's HIV patients were seen by the same doctors and nurses.

4.2 PARTICIPANTS

A total of 24 participants were recruited from two healthcare facilities in the Western Cape through purposive sampling. Purposive sampling allows the researcher to identify and select potential participants who can be deemed as 'information-rich' (Palinkas et al., 2013) due to their expertise or knowledge of a particular phenomenon. Purposive sampling was used to

identify healthcare professionals namely doctors (n=3), nurses (n=8), counsellors (n=1), sisters (n=2) and pharmacists (n=7) who work with HIV-infected youth and adults at both clinics. Alongside, support staff (two clerks and one data capturer) participated in the study as they were knowledgeable of the phenomenon under investigation.

4.3 PROCEDURE

Prior to the commencement of the study, I received ethical clearance from Stellenbosch University's Health Research Ethics Committee (HREC reference number: S18/10/209) (see Appendix M for ethical approval). Further, I obtained permission to conduct this research from the Western Cape Department of Health (see Appendix L and Appendix J and K for site approval letters). Several meetings were held with hospital management to procure permission for recruitment and data collection. Both healthcare facilities were approached in the planning phases of the project. Following ethical approval from the HREC and permission from the Western Cape Department of Health, meetings with the relevant contact persons at each of the healthcare facilities were held to make the necessary arrangements regarding recruitment and data collection**.**

In both healthcare facilities, I provided an explanation of the study and what would be expected of participants if they consented to participate in the study. Healthcare providers who were interested in participating were informed about the nature of the study and the risks and benefits of participation. I also explained to participants that participation in the study was entirely voluntary and that they could withdraw at any time without consequence. Furthermore, participants were assured of the confidentiality of their responses, and that all data obtained would remain anonymous.

In order to address objectives 1, 2 and 3, I conducted in-depth interviews with eligible participants. In order to address objective 4, I observed the clinic environment on paediatric and adult clinic days using naturalistic observation (Frey, Botan, & Kreps, 1999) (Appendix C).

Due to the time constraints of the participants, a once-off, in-depth interview was conducted per participant in this study. Flyers (Appendix H) were handed out to healthcare professionals by the clinic manager during their weekly staff meeting and also placed in the tea room. Interested healthcare professionals' completed a contact permission slip (Appendix I), to allow me to contact them and set up an appropriate date and time to conduct the interview. Participants did not use the contact slip but informed the facility manager about their availability and I could meet with them for the interview. The interviews lasted between 30 and 45 minutes (average time of interviews:40), and refreshment was given to each participant at the end of the interview.

The healthcare professionals working at clinic 1 and clinic 2 who agreed to participate in the study were required to consent to participate in writing. A consent form (Appendix D) was handed to the healthcare professionals ahead of their scheduled interviews to allow them the opportunity to read through the form and minimize time spent in the session with me. During the interview itself, participants were required to hand in their signed forms, and I could also clarify whether participants had any issues or concerns pertaining to the form. Only those who signed the consent form were interviewed. The steps followed in data collection after participants had provided written informed consent are illustrated in Figure 4.1 below:

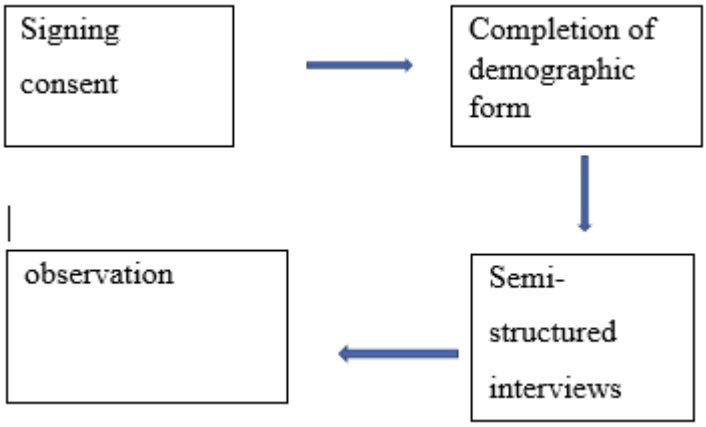

Figure 4.1: Steps followed in the data collection

Participants began by signing the informed consent (Appendix B), then completed a biographical questionnaire (Appendix A). Participants then participated in a semi-structured interview (Appendix D).

4.4 INSTRUMENTS

4.4.1 Demographic questionnaire

The demographic questionnaire (Appendix A) obtained information regarding the healthcare providers gender, age, name and surname, occupation, language, start time of the interview, end time of the interview and years of experience in this occupation.

4.4.2 Semi-structured interview

Phase 1: Interviews with healthcare professionals

A series of questions (Appendix B) were asked to each participant in a face-to-face interview session. The interview consisted of open-ended questions including their experiences of the healthcare system/process (e.g. “can you tell me about your experiences of providing HIV treatment and care to youth at your facility”), the transition process(e.g. “How is the transition

process usually handled?"), The experiences of adolescents (e.g. "What do you think has been the experiences of adolescents who are transitioning (or have already transitioned) to adult care?"), the facilitators to transition (e.g. "can you perhaps elaborate on what you think enables effective transition from paediatric to adult care of adolescents living with HIV? And explain why you think these things are important?"), the barriers to transition and suggestions on solutions.

The interviews were conducted in English and took place in private rooms at the facilities (TB room, Pharmacy counselling room, paediatric doctor room, adult doctor room). The interviews were audio-recorded (with permission) and subsequently transcribed verbatim by me and uploaded into ATLAS. ti - a qualitative software programme (version 8). The software allowed me to manage and code my data in keeping with my data analysis approach, described below.

4.4.3 Observation Schedule

Phase 2: Observation of the clinic context

I observed the paediatric clinic at Clinic 1, the adult HIV clinic at Clinic 1 and the mixed paediatric and adult HIV clinic at Clinic 2. I observed the clinic environment, the services, the interaction and the attitude of both adolescents and healthcare. I conducted between two to three hours of observation at a time, with intervals in between observations.

I often observed from the clinic waiting rooms, outside the clinic, by the clinic corridor or at the pharmacy waiting rooms of the clinics between 9 am to 13:00 pm on Mondays and Thursdays for a period of two months. I was able to observe the interaction of all the parties in the clinic. I used a semi-structured observation schedule to guide my observations at the clinics (Appendix C). I was at Clinic 1 on Mondays and at Clinic 2 on Thursdays. I used a notebook and a pen to capture my observational notes.

4.4.4 Data collection

Following the research procedure as described above, recruitment and data collection were conducted from the 4th of March to 25 of April. The intended sample size of the study was 20 participants; however, 24 participants were recruited. I could have recruited an additional four healthcare but due to their work schedule, they were not available. Interviews were conducted in English but five of the 24 participants (n= 2 Afrikaans and n=3 Xhosa speaking) indicated that they could have expanded more on the topic if they were interviewed in their mother tongue, in this case isiXhosa. Some of the interview sessions (n=3) were disrupted by a phone call in the room, the noise of a loudspeaker in the waiting room and the unexpected walk-in of healthcare staff in the interview room.

4.5 DATA ANALYSIS

For the purpose of this study, I undertook a thematic analysis of the data using the six phases as recommended by Braun and Clarke (2006). Thematic analysis allows for the identification, analysis and reporting of patterns (themes) within data (Braun & Clarke, 2006). The thematic analysis provides a method of analysis in which the researcher has freedom in determining what is important in the data and what constitutes a theme, as is not necessarily bound by a pre-existing coding or theoretical framework. The themes identified are therefore inductive, and driven by the data. Once the data analysis has been conducted, the researcher can then return to the literature, in order to interpret the data within a particular theoretical context. Qualitative research can be criticized as allowing for an ‘anything goes’approach in data analysis (Antaki, Billig, Edwards, & Potter, 2002, para. 6), as the flexible approach may lead to inconsistencies and a lack of coherence in the analysis (Nowell, Norris, White, & Moules, 2017). However, thematic analysis, as conceptualized by Braun and Clarke (2006), provides a step-by-step approach to thematic analysis, enabling transparency in the analysis process, allowing the researcher to make their method of analysis explicit. It includes six phases, namely:

(1) “familiarising yourself with your data”; (2) “generating initial codes”; (3) “searching for themes”; (4) “reviewing themes”; (5) “defining and naming themes” and (6) “producing the report” (Braun & Clarke, 2006, p. 87).. The interview and observational data were triangulated for coherent justification of the themes (Christensen et al., 2011; Cohen & Manion, 1997).

The thematic analysis in the present study consisted of the following six phases:

Phase 1 required me to become familiar with the data through several readings and subsequently to transcribe the data while noting ideas (Braun & Clarke, 2006).

This phase consisted of transcribing, translating, and repeated reading of the interview transcripts. After collection of the data before transcribing, I would listen to the interviews to ensure that I was familiar with the language, style, and content of the audio recording. I then transcribed the recording verbatim, after which I listened to the recording again, and reviewed the transcript in order to ensure accuracy. After the transcribing was complete, I read through each interview again. In order to keep the written text as the true to what the participant had said, I refrained from correcting the language use errors while transcribing. All the transcriptions were then imported into ATLAS.ti software once I became certain that all interviews were correctly transcribed and translated. Throughout the re-reading of the transcripts, I used ATLAS.ti’s memo function in order to note what participants were saying and particular points of interest, as well as to generate initial code ideas. Throughout the process, I had already begun to organized possible themes based on predominant ideas in the data.

Phase 2 consisted of producing initial codes. I systematically coded interesting features of the data across the entire data set in an order relevant to each code (Braun & Clarke, 2006). A list of early code ideas was created, in order to create as much structure in the analysis process from early on, which allowed for a systematic analysis. I then began the first round of coding, coding all relevant quotations. Throughout this process, codes were added to and removed from the initial list, and changed as necessary.

Phase 3 consisted of searching for themes. I classified codes into possible themes and gathered all data relevant to each potential theme (Braun & Clarke, 2006). Throughout this phase of the analysis, I organized codes into four broad candidate themes, relating to the barriers to and or facilitators of transition from paediatric to adult care according to the healthcare providers perspectives. In order to organize the data into potential themes, I used the code group manager function in ATLAS.ti to group my codes. Codes were also colour coded to indicate the broad theme of which they formed a part. Throughout this phase, I merged and changed codes in order to refine and make the analysis more consistent. Redundant codes were refined or removed. The coding was reviewed during this process by my supervisor.

Phase 4 consisted of reviewing the themes. Themes were checked in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis (Braun & Clarke, 2006). The network function in ATLAS.ti was used to help to select the theme in relation to the theme under which they were grouped. After reading through the extracts for each theme, it was evident that four of the candidate themes, namely the:

- understanding and conceptualization of transition, the individual factors affecting transition, and

- the healthcare system factors affecting transition, social factors affecting transition needed to be further refined and sorted into 10 subthemes.

Once I was satisfied with the first level of review, I continued with the second level of review. The final review of the themes consisted of determining whether the identified themes were an accurate reflection of the meanings presented in the entirety of the data set.

Phase 5 consisted of defining and naming the themes. A continuous analysis of the themes allowed to refine the particularities of each theme (Braun & Clarke, 2006). Once I was satisfied that the themes identified represented the data, I named the themes and subthemes. The

naming of the themes was an iterative process, beginning in phase 3. As indicated, four themes were identified in the data, namely, (1) understanding and conceptualization of transition; (2) individual factors affecting transition; (3) health system factors affecting transition; (4) social factors affecting transition. These themes were additionally organized into subthemes.

Phase 6 consisted of generating a report. Selecting rich, compelling data extract examples that relate to the research question and the literature and a final analysis of the selected extracts were included in the report.

The final phase involved presenting the results of the analysis, having selected compelling data extracts from the data to illustrate the themes. The findings of the study are presented in Chapter 5. It should be noted that in reporting on the findings, all participants were assigned codes. One of the main advantages of this thematic analysis was its flexible approach that facilitated the navigation across a range of epistemologies and research questions (Braun & Clarke, 2006). One of the disadvantages of using the thematic analysis was, the inability of the researcher to retain a sense of consistency or contradiction throughout an individual account, and such contradictions and consistencies across individual accounts could be revealing (Braun & Clarke, 2006).

- **Trustworthiness in qualitative research**

To better understand the topic under investigation, interviews and observational data were analysed side by side inductively through triangulation. As it is suggested by Shenton (2004), in qualitative research trustworthiness is often questioned, because of the difficulty in addressing issues of reliability and validity. Additionally, qualitative thematic analysis flexible approach, as employed in the present study, was subjected to various criticisms, as were discussed. Therefore, qualitative researchers must be able to demonstrate that data collection and analysis has been conducted in a manner that is “precise, consistent, and exhaustive” (Nowell, Norris, White & Moules, 2017, p. 1) by recording in a systematic way the methods used, and

revealing these in more detail. This allows the reader to audit the analysis conducted by the researcher (Koch, 1994), and determine the trustworthiness thereof. Guba and Lincoln (1981) provide a number of criteria for ensuring and assessing the trustworthiness of naturalistic inquiries, including qualitative research is provided by Guba (1981), as well as Lincoln and Guba (1986). The writers identified the following criteria: credibility, transferability, dependability, and confirmability. These criteria are discussed below in relation to the data analysis of the present study.

- **Credibility**

Credibility refers to the congruence between the respondent's opinions (reality), and the interpretations of the researcher (findings) (Tobin & Begley, 2004). To ensure credibility, participants checks must be conducted (Guba, 1981). For example, one way of conducting checks could consist of the researcher asking clarifying questions to participants during the course of the interview (Shenton, 2004). In this study, I asked clarifying questions when I felt (i) what a participant said was unclear, and (ii) in order to make sure that I had a precise understanding of their responses. Furthermore, encouraging participants to be honest during the data collection process can assist with credibility (Shenton, 2004). In order to elicit data that were as true to the reality as possible, I created rapport with my participants and reminding them that there were no right or wrong answers to pose questions. Additionally, credibility can be addressed by employing methodological triangulation and investigator/analyst triangulation. Patton (1999) indicates that studies using only one method of data collection are more vulnerable to the errors tied to that particular mode of enquiry. In this study I ensured triangulation of the data by conducting a naturalistic observation of the subjects and clinics (see Appendix C; observation schedule). This was used to contextualize the findings from interviews data. Additionally, as indicated, analyst triangulation is essential to ensure credibility, as it can help in reducing bias that may arise as a result of a single individual analysing the data. In this study, my

research supervisor reviewed my qualitative data analysis in order to ensure that my interpretation was consistent with what the participants were reporting.

- **Transferability**

Transferability denotes the generalisability of a study's findings. However, naturalistic ways of enquiry, such as qualitative methods, do not strive to make claims of applicability, and should rather aim at providing a rich explanation of the phenomena at hand (Guba,1981). In this study, I tried to do so by using purposive sampling, a method recommended by Guba (1981), to identify participants that fit the study's eligibility criteria, and that would be able to provide a rich account of the phenomenon of study. Additionally, I was able to collect thick descriptive (Guba,1981) data by describing the study sites, collecting demographic information on the sample, and conducting naturalistic observations.

- **Dependability**

Dependability denotes the extent to which findings of a study are consistent and replicable. Given the changing nature of the phenomena under investigation, it might be difficult to achieve dependability when it comes to qualitative research (Shenton, 2004), and it might be irrelevant to the field (Guba & Lincoln, 1981). However, such issues must still be addressed, and it is therefore important that the methods employed in qualitative studies are reported on in detail (Shenton, 2004), ensuring that the steps taken in research are logical and well documented (Tobin & Begley, 2004). In this study, I thoroughly documented the research plan and execution thereof, making clear the methods used in data collection and analysis, as was presented in this chapter.

- **Confirmability**

The objectivity of the study is crucial in qualitative research (Guba & Lincoln, 1981). In keeping with the preceding, the researcher must strive to ensure that the results reported are reflective of the experiences and views of the participants, and are not the result of the predispositions of the researcher (Shenton, 2004, p. 72). To ensure that confirmability of a study is achieved; the criteria of credibility, transferability and dependability should have all been met (Guba & Lincoln, 1981). Furthermore, in addressing the issues of confirmability, the researcher must acknowledge their positionality within the research and provide a description of their experiences (Koch, 1994). One way in which the researcher can provide description of own experiences is by keeping a journal (Koch, 1994). Additionally, the researcher must provide information regarding their training and preparation (Patton, 1999). When beginning this research project, I had previously (3years earlier) completed my Honours degree in Psychology. I also had experiences in interviewing people as it formed part of my profession. However, I was relatively inexperienced in the field of the current research study, I had previously completed a qualitative research project as a component of my Honours degree. In order to prepare for the current study, I read extensively on research on barriers and facilitators of transition from paediatric to adult care of HIV infected adolescents as well as on the history of HIV amongst the adolescents and the healthcare system. Moreover, I went through the interview questionnaires with my supervisor. As indicated, I did not have much research experience when I stated this study, yet I attempted to mitigate this by preparing thoroughly for data collection, ensuring that I was familiar with the study protocol, practising the demonstration numerous times, and familiarising myself with the measures used. During data collection, I took field notes of my experiences at the sites and in sessions conducted with participants, in order to be able to reflect thereon, particularly in terms of how I assumed participants may have perceived me. I was aware of the fact that I was an ‘unfamiliar face’ to participants, who were accustomed to dealing with

the regular clinic staff and doctors. While conducting naturalistic observation I felt stigmatized sitting in a specific space allocated for patients with HIV; I also felt that those patients felt stigmatized by my presence. I noted that some participants assumed that I was a professional researcher with years of experience in the field of research. Some healthcare staff who were not part of the study referred to me as a healthcare professional. Few nurses (n=2) assumed that I was a doctor. Moreover, whilst some of my participants were older than me, they appeared to view me as an authority figure. Patton (1999) notes that the presence of a researcher may create a "halo effect" (p. 1202), which could cause participants to behave in a certain way, and perhaps "show off" (p. 1202). In the particular study, participants' assumption that I was a doctor may have led to inflated levels of self-reported adherence, or participants not providing an honest account of their experiences, based on the information they may have assumed that I was hoping to obtain.

4.6 ETHICAL CONSIDERATIONS

For the purpose of this research, the following ethical guidelines were adhered to:

Anonymity and confidentiality: In order to achieve this in the present study, special code identifiers were used in place of participants' names, and information obtained from the research participants were not revealed outside the research group (Creswell, 2013). All documents, study materials (audio-recordings, transcripts) and participants' information were locked in a cabinet in the Department of Psychology, and only my supervisor and I had access to these data. The anonymous transcripts were available to my supervisor. The digital audio recordings and the transcripts of the interviews were kept secure, as per university policy.

Informed consent and autonomy: Potential participants had to sign an informed consent form (Appendix D). Each participant was provided with a written informed consent prior to participation, to ensure that they understood the research and any risks involved with participation. I assured participants that they did not have to answer any questions they felt

uncomfortable with and could terminate the interview at any time should they become uncomfortable, I emphasized that participation was voluntary. Participants were free to withdraw from the study at any stage. This study posed no risk to the physical health of participants.

Ethics clearance and permissions: Ethics clearance was obtained from the Western Cape Department of Health (Appendix L) and Stellenbosch University Health Research Ethics Committee (HRECS18/10/209) (Appendix M). Permission was obtained from the gatekeepers of both clinics. Initial permission to use these facilities as sites of recruitment was obtained (Appendices J and K).

CHAPTER 5

RESULTS

5.1 INTRODUCTION TO CHAPTER

In the following chapter, I present the results of the study comprising three sections. Firstly, I report on the demographic characteristics of the sample of participants recruited from both sites A and B. Secondly, I report on the themes and sub-themes that I identified following thematic analysis of the interview data with 24 participants. In this section, I document the barriers to and facilitators of transition from the perspectives of healthcare providers.

5.2 DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

As presented in Table 5.1 below, the sample of my study consisted of 24 participants the majority of whom were female (n=21). Participants were mostly healthcare professionals including nurses (n=8), doctors (n=3), pharmacists (n=7), counsellors (n=1), and operational manager sisters (n=2). Further, it was recommended to me by the operational manager that I include the perspectives of other support staff namely the HIV data capturer (n=1) and administrative clerks (n=2) as they were also informed about issues related to my research and could provide me with useful information. All participants were interviewed confidentially in a place mutually agreed upon at the clinics. Participants were assigned a code to maintain anonymity. Interviews lasted between 30 and 45 minutes (average time of interviews: 40 minutes); the sample characteristics of participants recruited in this study are summarized in Table 5.1.

Table 5.1:

Demographic Data

Participant Code	Occupation	Gender	Age	Years Experience	Site
1	Nurse	Male	39	2	1
2	Pharmacist	Female	32	8	1
3	Pharmacist	Female	43	15	1
4	Medical doctor	Male	32	4	1
5	Clinical nurse practitioner	Female	55	20	1
6	Nurse CNA	Female	47	9	1
7	Clinical nurse practitioner	Female	62	18	1
8	Primary Healthcare Sister	Female	48	25	1
9	Staff nurse	Female	55	+/- 20	1
10	Hast adherence counsellor	Female	48	3	1
11	Professional Nurse	Female	60	30	2
12	Registered nurse	Female	57	10	2
13	Enrolled nurse assistant	Female	50	9	2
14	Ward Clerk	Female	39	2	2
15	Data capturer	Female	38	1y and 4 months	2
16	Medical Doctor	Female	49	25	2
17	Operational manager outpatients(sister)	Female	42	10y +	2
18	Pharmacist	Female	42	19	2

Participant Code	Occupation	Gender	Age	Years Experience	Site
19	Pharmacist	Female	26	3y and 3months	2
20	Pharmacist	Female	58	14	2
21	pharmacist	Male	58	10	2
22	Pharmacy manager	Female	61	34	2
23	Admin clerk	Female	30	5	2
24	Doctor	Female	35	5	2

Note: [CNA: clinical nurse assistant]

5.3 QUALITATIVE THEMATIC ANALYSIS RESULTS

In this study, I conducted semi-structured interviews with 24 participants the majority of whom (n=21) are HCPs to adolescents living with HIV. These HCPs were recruited from two different healthcare facilities, either Clinic 1 or Clinic 2. The interviews were guided by an interview schedule consisting of seven open-ended questions (see Appendix B.) Following steps for thematic analysis, I identified four superordinate themes and 10 sub-themes. The themes and sub-themes are presented in Table 5.2.

Table 5.2

Themes and sub-themes

Theme	Sub-themes
Understanding and conceptualization of transition	• Age of transition • Meaning given to the process of transition • Roles and responsibilities of all parties in transition
Individual factors affecting transition	• Perspectives on adolescents' experiences of transition • HIV knowledge as a barrier and facilitator of adherence • The issue of HIV disclosure
Healthcare system factors affecting transition	• Day-to-day facility functioning • Counselling as a facilitator of transition • Disruption to continuity to care
Social factors affecting transition	• Poverty and lack of resources.

5.3.1 Theme 1: Understanding and Conceptualization of transition

In this section, I discuss the 3 sub-themes related to participants' understanding and conceptualisation of transition namely, age of transition, meaning given to the process of transition, and the roles and responsibilities of all parties in transition

5.3.1.1 Age of transition

Participants reported that for them, signs of maturity amongst adolescents with HIV played an important role in readiness to transition, more so than their age. Further, participants reported that when it came to transitioning and determining readiness, there was no specific cut off age that they were aware of and adolescents in their care were usually transitioned between

12 and 19 years of age. Further, healthcare providers from both paediatric and adult healthcare services reported that the decision to transition was usually made by the doctor. Doctors in this study who had transitioned adolescents before reported that their decision was usually based on the adolescent's age, their weight, a good medical history, consistent adherence to ART and a good CD4 count. A doctor working with both paediatric and adult HIV patients said:

> *The transition to adult care is not that much, except that your visit intervals become longer. So, if we see someone who is stable, who is virologically suppressed, doing well so to speak, we will give [them] a script for six months. They will present every two months to collect their medications. Then after six months, they will see the sister; if there is any problem, the person will be referred back to me and if not they will get another six months and then see the doctor after one year but remember that is for stable, that is not for everyone* (Doctor – 4).

Doctors reported that some adolescents who have reached the age of 18 were still retained in paediatric care because of problems related to mental ill-health, mild disability and low levels of maturity. For example, one doctor (age 35 with 5 years of experience in working with adolescents) stated:

> *So we will say to them, for example, this is a 17-year-old, she got some mild intellectual disability; she is still in grade 10. So we would like to keep onto her even though she is 17 and they say ok until you are ready to hand it over that is fine. Versus, for example, this is an 18 years old girl she is finish school she is pregnant now she is staying with her boyfriend she is functioning as an adult we will like to transition her to your care they say they are happy* (Doctor – 24).

One adult doctor in clinic1 explained that adolescents who became pregnant were transitioned to adult care irrespective of their age. Further, doctors reported that paediatric defaulters who returned to treatment at the age of 20 or older were also immediately transitioned to adult care, and this was usually referred to as an 'Ad hoc' transition to adult care. For example, one doctor working with adolescents in an adult clinic1 stated:

> *So we have two cases: one is if [a]a girl falls pregnant, they are no longer seen by the paediatric doctor. So at whatever age she falls pregnant, it is always a disaster when they fall pregnant. But then, one of the paediatric doctors will then come down to our adult clinic and ask us if we could take over management. Or the other case is when they start to get older and it depends; but usually, raptly around 18, 17 to 18 and then again, they just come and say can we book them for the adult clinic next time they are due to come?* (Doctor – 16).

5.3.1.2 Meaning given to the process of transition

Nurses and pharmacists who took part in this study did not seem to be familiar with the concept and the process of transition. For some of these participants, the process of transition meant a change in medication regime; usually a change from multiple doses and medications to a fixed-dose combination. For other nurses and pharmacists, transition meant a change in clinic or doctor. While others simply did not know what transition was and had never heard of the term transition before. In clinic 1, some doctors, pharmacists, sisters, nurses and additional staff described the process of transition as a verbal hand over of care. Participants recounted that the verbal hand over usually meant that the paediatric doctor would accompany the transitioning adolescent to the adult services and introduce them to the relevant staff. However, this was not always the case and sometimes adolescents had to enter adult services alone. Participants suggested that proper hand over would allow adolescents to get to know and familiarize

themselves with the adult healthcare staff which would go a long way in reducing confusion and building trust. This nurse also added that in her experience not having a proper handover process made adolescents feel scared and uncomfortable and this hindered successful transition. One pharmacist aged 61 with 32 years of experience said:

> *I think there must not just be a verbal [handover]. Tell the child, 'I am sending you [to the clinic]' and then I would like to take the child, introduce the child and say this is where you gonna go. Introduce the child, these are the doctors and these are the counsellors. It should be a physical hand over not just like a paper hand over* (Pharmacist – 22).

A ward clerk aged 39 with 2 years of experiences said:

> *What the doctors do is they tell the child before coming of age, 18 they will say like next year he is 17. They will say like next year you are going over to the adult side. You are not going to be seen by us anymore but there is a doctor and we hope that you will adjust. That is what they tell them and some of them can come and bring them over to this site so that they can familiarize with it. But like I said from personal experience these children will say now we must sit amongst the adults we use to sit in this side we use to be seen in the rooms and now everybody knows what we are coming for* (Ward clerk – 14).

One of the adult doctors explained that there was no existing policy or guideline on transition in their facility and that handovers were usually verbal. She said:

> *We haven't implemented anything other than just vocally. If they ask us to take over and then it is documented on the file and that the next visit they are to transition across to adult ARV's clinic* (Doctor – 16).

Similarly, another doctor (aged 32 with 4 years of experiences in working with both paediatric and transition HIV adolescents) stated that:

> *To facilitate the transition, a lot of time what we are doing is not really [according to] a policy per se on paper that says ok this is how we will manage ARV's patients who are now transitioning to adult care* (Doctor – 4).

One of the paediatric doctors was able to detail the process of transition more carefully and stated:

> *Usually there is only a formal introduction when we transition them. So in other ways they might have accompanied their mom previously at the adult doctor, but we don't count that because we were not usually involved in that process. For us we want to make sure that we and the adult doctors are in the same place when we introduce the child to them to take over. It is usually a little bit informal; usually, we explain to the children it is time for you to now move over to the adult [doctor], are you happy with that? And they are happy with that. We usually walk over and say this is doctor so and so and you are going to be in this room from now on for your ARV's* (paediatric doctor- 24).

5.3.1.3 Roles and responsibilities of all parties (caregivers, nurses, doctors, counsellors and pharmacists) for the facilitation of transition

Doctors and nurses reported that, transitioning periods were sensitive and adolescents needed good preparation and support from both healthcare providers and parents. One doctor said:

> *We don't always appreciate that this is a sensitive phase and not all people are trained actually. It is not really something that we focus on it definitely deserves more focus* (Doctor – 4).

In terms of caregiver support, participants explained that having a caregiver who consistently accompanied the adolescent to medical consultations usually helped when it came to transition. A stable and consistent caregiver meant that at the time of transition the adolescent would have the support of a caregiver who was familiar with their treatment and could help guide them through the transition. A doctor who had some experience in working with adolescents who had transitioned stated:

> *Continuity from the parents' side is important as well because what we find out a lot of time is that the parents will send the child with the aunt- then in the next visit grandmother comes. So they don't really know what is going on. They don't really know they don't understand the seriousness of the situation* (Doctor – 4).

Doctors suggested that, there should be continuity to care from parents for example, continuous mentoring of adolescents after transition to adult treatment; maintaining good relationship and environments with the adolescents. Participants advised that, parents should be open to communication, strive to make their children understand the reality about the disease by discussing topics related to HIV. In addition, participants advised that, parents should be supportive, accountable towards their children and show a good example in term of compliance to treatment, clinic appointments reporting medication side effects and defaults or risky behaviour to the HCPs.

Nurses, counsellors and pharmacists reported that adolescents who came from homes where a family member abused alcohol were either rejected, did not receive support, or were exposed to stigma and their families were more likely to divulge their HIV status to others outside the home. Participants observed that many adolescents coming from homes with a substance abuse history were missing their clinic appointments, were non-adherent to treatment and were taking "drug holidays". Adolescents coming from these homes were more likely to

engage in substance abuse and become defaulters thus hindering their transition from paediatric care to adult care. A nurse aged 60 with 30 years of experiences in working in the HIV adult clinic sated the following:

> *If they are drunk, they tell everybody this one is HIV positive wa wa all those things and then that is not good for the patient. We have experienced those things even when they are disclosing we do tell them they must not disclose to a person who is drinking [or] talking too much because he is gonna embarrassed her at some [point]* (Nurse-6).

Participants considered overprotective home environments as a barrier to transition. Doctors, nurses and pharmacists reported that adolescents coming from over-protective families were difficult to transition. They explained that some parents or caregivers did everything (e.g. were always giving medication, reminding, attending clinic appointment) on behalf of their adolescent because they did not trust in the maturity and ability of their adolescent. Consequently, adolescents experiencing over protectiveness felt less involved could neither take responsibility for their own health nor develop self-management skill necessary for their transition. A pharmacist aged 61 years with 34 years of experience stated the following:

> *Maybe not trusting the child to take their own medicine. Because the mother, the father the carer or the grandmother has been taking care of the child for so long that they can't let go you know they are still interfering with the kid medications* (Pharmacist – 22).

Pharmacists, nurses and doctors reported that some parents did not want to follow-up the health of their adolescent once they transitioned because they were tired, wanted to relax and focus on their own lives and have financial relief. A pharmacist aged 61 years with 34 years of experience stated:

> *Money, because the family doesn't have money, transport right? and remember this is a chronic thing right? So yes this mom has now for how many years you know and it is just going on, and I think any mom wait till the point where you can just relax a little bit and not be so you know. When you are becoming old now you can be on your own, not self-sufficient but actually go alone. I can't go remember that every time that their coming there is a sacrifice, is either I cannot be at work or is money cost for me and you to be here because it's time, because and also taxing on the others children* (Pharmacist – 22).

Participants reported that part of the plan to transition adolescents to adult care would need to include information about what adolescents can expect from adult services. Participants reported that adolescents' paediatric doctors should assume the responsibility of explaining this to adolescents. A 50-year-old enrolled nurse assistant stated the following:

> *I think they need to do proper preparation for them to transit. Because sometimes you can see in the character that, they don't want to belong to that group, because they were so used to their previous group. I think maybe if we do good preparation instead of saying to them you are 18 years old now, you are young adult, you need to go to that group. I am saying things that I hear doctors saying to patients; you don't belong to the paediatric anymore; you are grown-up now. It is the way we say it because sometimes, the way we say things can put people off. So, I think if we do it in a better way, you are preparing the child from 15 years old and say listen, you have done well, there should be a stage at the age of 18 if you still doing well* (Enrolled nurse assistant – 13).

Participants reported that adolescents should be prepared for the moment of transition as early as possible and that they should not only be informed of this at the end when it happens.

Participants reported that part of involving adolescents early on meant including them in the consultation conversation. Participants explained that when children are young, caregivers usually engaged doctors during consultations. Participants explained that communicating directly with children about their treatment during consultations would facilitate the transition and help shift responsibility to the adolescent. One of the paediatric doctors stated:

> *So, we are transitioning from you asking mom what is going on with the child? and the mom says this is what happens; to we talk to the child himself how are you doing? how do you feel about the medication? and the mom should take the back seat in the consultation room. We sometimes have that, the moms answering all the questions on the adolescent behalf because the adolescent is quite withdrawn or shy and that ends-up the process of taking responsibility* (Doctor- 24).

A pharmacist with 19 years of experience in working with HIV-infected adolescents stated:

> *It is a very individual thing; so, I think if you want a smooth transition, you need to be able to get the individual to a point where they take 100% responsibility for their own health. That, they understand the medications and the treatment and you know that they comply with that treatment* (Pharmacist – 18).

Some nurses and doctors felt that HCPs in the adult services have to keep adolescents motivated by mirroring a positive, supportive and encouraging attitude. Participants reported that a positive, supportive and encouraging attitude from HCPs in adult services could promote trust and openness in the transitioning adolescent and facilitate treatment adherence after their transition. Further participants advised that, to facilitate transition HCPs should motivate adolescents by putting more emphasis on the benefits of the adult clinic when they are preparing

adolescents. For example, HCPs can talk about the flexibility in the time of appointments, the decrease in clinic days and reduced volume of medication. A 50-year-old nurse said:

> *Because the process is faster in the adult clinic, I think that we can use that as motivation. Based on the adolescent and say listen you used to be in the previous clinic where it took you longer, because [paed is] is consultation is longer than the adult. And say to you maybe you are the patient you can join; because you are doing well, you are doing fine, if you go to the paed clinic. [And] and sometimes knowing what the patient is doing like [is] is the patient a student? is the patient on college? to encourage the patient that, if you transit now from this point to that point that your time will be lesser, you don't have to wait so long. You can make use even you can make use of the body system where someone else can collect [your] your tablets or you can change the dates that is suitable for you* (Enrolled nurse assistant- 13).

5.4 INDIVIDUAL FACTORS AFFECTING THE TRANSITION

5.4.1 Perspectives on adolescents' experiences of transition

Doctors, nurses, pharmacists, the counsellor and registered sisters explained how, in their opinion, adolescents experienced the process of transition. These participants explained that adolescents often experienced transition as a rejection from paediatric doctors. Consequently, some nurses reported, that some of the adolescents were giving up on their treatment because it was no longer important to them. A paediatric doctor stated the following:

> *If you don't make an effort in explaining to the adolescents why you are transitioning them to a different doctor, they might see it as rejection. They might see as ok we don't want to manage you anymore or we will send you to other doctors; we want to spend our attention with other patients. So the*

> *adolescents that have feeling of rejection that feeling might stand as a barrier for him to transition. Yes, then he might say well if the doctor that always see me doesn't want me fine then I don't want to take my treatment that kind of attitude* (Doctor – 24).

Doctors, nurses, counsellors and pharmacists reported that there were adolescents who shared a positive view about transition. They explained that adolescents who knew that they were becoming independent and responsible, felt excited about this new phase in their lives. Participants reported that adolescents who had a positive view were easy to transition. One participant stated:

> *Experiences again it differs. Some are comfortable because they are now transitioning into adulthood. They are excited, they can make a decision for themselves* (Ward Clerk - 14).

Participants also explained that adolescents who were struggling emotionally were less likely to transition well. Here participants meant that, in their experience, those adolescents who were struggling with feelings of anger, fear and denial related to their status and treatment were more likely to become tired of taking their medication, presumably related to poor motivation to adhere which could disrupt transition. A pharmacist in clinic 1 indicated that, for adolescents who were doing well on treatment, continuing taking medication while healthy made them feel like they have lost their self-worth. She explained that such adolescents abandoned their treatment to regain their self-worth which made them feel important. She stated:

> *I don't think so much is ignorance I think they are aware that if I don't take my medication, I'm going to get ill. I think is more just a natural feeling they need to have their self- worth, I am still important whether I take these tablets or not it's not the end of the world I can live a normal life and, I think growing-up*

> *and going into a job situation where maybe you have to declare you know I have HIV it is a whole lot of fears* (Pharmacist – 22).

Participants reported that HIV-infected adolescents wanted to be like their non-HIV infected peers. They wanted to behave and do things like their non-HIV peers since they were healthy looking. An outpatient sister in the adult clinic stated the following:

> *[An] adolescent is a child, he doesn't want to be different from anybody and from peers. It's such a big thing I am different if I have to go to the clinic every month, I am different if I have to drink medication every day, I'm different if people see me doing that* (Outpatient sister – 17).

Participants explained that the desire to feel normal meant some adolescents were living in denial and were difficult to transition especially when they defaulted and did not return to the clinics for care. Further participants reported that some adolescents felt that being HIV-positive and constantly having to take medication and attend the clinic made them feel as though they were missing out on being a teenager. These feelings would result in disengaging from care. A doctor with 4 years of experience stated the following:

> *They have now come to a questioning phase and it is difficult for them to accept that I was born with the diagnosis I mean it's only you didn't ask for this diagnosis and now you are presented by the situation you are in there is a lot of anger* (Doctor – 4).

Some doctors, nurses and pharmacists were of the opinion that transition might be hindered by hormonal changes that happen during adolescence. The changes in hormones often meant adolescents were moody, would seek instant gratification, and become rebellious, impatient and unable to handle pressure. Consequently, participants reported, some adolescents

were not yet ready to take on such an important role (i.e. take responsibility for their own treatment and care). A pharmacist said:

> *Also they are hormonal, they are moody, there is nothing we can do about. We just have to wait for them to get through with the hormonal changes. Because you know sometimes you don't feel like taking medicine* (Pharmacist – 22).

5.4.2 HIV knowledge and impact on transition

Participants reported some adolescents knew of their HIV status and were knowledgeable about HIV, and others did not. Good knowledge of HIV and awareness of HIV status acted as facilitators of transition. Participants also explained that some adolescents (those who knew their status) were sceptical of the HIV diagnosis, as they could not recall any symptoms of being ill or any memories of being diagnosed. Participants also reported that adolescents' knowledge and beliefs about HIV was often influenced by what they had learned in school or from others. Participants explained incorrect knowledge was likely to hinder transition. One counsellor stated:

> *But I recently had students that come and they will tell you that there is a cure and when you explain to them we are not concentrating on the cure right now. We are concentrating on keeping you lower than detectable. They will tell you that, there is a cure. So it's difficult to handle that […]* (Counsellor- 10).

Participants reported that some adolescents no longer considered HIV a serious issue since people were no longer dying of it. Consequently, participants explained how adolescents engaged in unprotected sex to feel normal, accepted and avoid stigma. One participant a pharmacist recalled what an adolescent had told her:

> *I can have unsafe sex you know, I can be promiscuous, I can go and have sex because you know it is stigma I am not gonna die anymore of HIV* (Pharmacist – 22).

Participants reported that the lack of knowledge on HIV meant some parents, caregivers and adolescents deny their HIV status and engage in alternative treatment or mix their treatment. Participants reported that adolescents were given traditional treatment concoctions from Sangomas to drink or were given both traditional treatment and ARV's. One nurse explained that that mixture of treatment was detrimental to the health of the HIV adolescent and hindered transition. A participant in Clinic 1 stated:

> *Some of the people they will think, they won't think as if these are side- effect I hope you get what I am saying? They won't think that these are side effects. They will think that now they are bewitched you see what I mean? Whereby someone will go and consult their what [what] can I say their traditional healer or what so ever you see what I mean? and then, he gona get some medication, traditional herbs there or all this kind of things. Of which mean when he is coming and drinking his tablets those herbs that he got it from Sangoma or whatsoever they gona they not they gona contradict with medication that he gets for HIV and AIDS you see what I mean? And that also can hinder the process. I hope you get myself* (Nurse – 1).

Additionally, participants reported that in some cases where parents, caregiver or adolescents lacked knowledge of HIV, they perceived ARV's side effect as witchcraft and opted for treatment through concoctions given by Sangoma's. A nurse in clinic A reported the following:

> *I think some of the people they've got their own understanding that HIV is non-existent. They don't believe inside effect they considered them to be a bewitch* (Nurse – 1).

Participants reported that parents/caregiver who understood the disease and communicated regularly with their child about medication times and clinic appointments were

able to prepare them to become responsible for their own health. Participants indicated that adolescents coming from those type of families were doing well and transitioned successfully. Participants also reported that, parents or caregivers who lacked HIV knowledge were less likely to be supportive and sometimes stigmatized or discriminated against their adolescent which led to disengagement from care. One participant said:

> *So we encourage the mother actually to when they are at home to talk about HIV to not have this be a dirty secret so if there is a character on the TV that's got HIV that usually a nice stepping stone to start approaching the subject* (Doctor – 24).

5.4.3 The issue of HIV disclosure

Participants reported that disclosure was a key element for a successful transition from paediatric care to adult care of HIV infected adolescents. A counsellor in this study added that disclosure was important in her work as a healthcare provider and for the well-being of the HIV infected adolescent. She explained that successful disclosure allowed adolescents to comply with their treatment and access support necessary to facilitate transition. Healthcare providers explained that most parents did not feel comfortable to disclose their child's HIV status to them and requested the assistance of doctors and nurses. One participant stated:

> *…So disclosure in our work is very important. For instance, if it could be possible that the nursing staff could have the right to give disclosure but if the child is positive we can call the mother and tell the mother the child is positive so that the mother knows* (Counsellor- 10).

Participants emphasized the importance of maturity among adolescents and good relationships before disclosure took place. Based on their interaction with their HIV-infected adolescents, HCPs observed that those who were mature and had good relationships with family,

relatives or HCPs were more receptive to disclosure and transitioned smoothly as opposed to those without good relationships.

> *It is about [for the for] the person self –acceptance, self-acceptance knowing that life doesn't stop at childhood you are growing and as you grow you must transit from one point to another point. Family involvement, us on the other side been trying to be helpful us health workers help* (Enrolled nurse assistant – 13).

Another participant stated:

> *Well you need to have a very motivated parents. You need if both parents are present great and we do find those parents were mom and dad come together and they understand each other's and there are no problems. So the family unit and there should be pressure some pressure from the parents. Because at that level you are still not ready to be an adult. So they need to be looking at the back of the child. So I mean in a very motivated family children do quite well* (Doctor – 4).

Conversely, adolescents deemed as immature by participants or those coming from an unstable home or non-caring family were more likely to rebel, stop the medication, stop attending clinic appointment and sometimes even engage in risky behaviour. Participants reported that the above factors acted as barriers to transition. A doctor with 25 years of experience working with HIV patients stated the following:

> *Continuous nurturance constitutes a barrier to transition. I suppose if the caregiver or family they still consider the adolescent as a child and refuse to allow them to progress towards adulthood; they might prefer them to be at the*

> *paediatric clinic and therefore it will be a barrier to say actually my child is now adult he needs to be seen in adult clinic* (Doctor – 16).

In order to facilitate transition, some healthcare providers suggested the implementation of the support, through adherence youth support clubs, as a way to help adolescents to come together share their worries and receive support and education about their health condition. Other participants indicated that support groups were not a good idea as adolescents did not want to belong to such a group as they feared disclosure. Another participant stated the following:

> *…We tried to open the group, what did you call? Support group but it never worked. So they never came you understand? Then I ask them why you didn't come? They said no sister that one will know me that I am HIV that one will know I am HIV. We did try that but it never worked* (Nurse- 6).

Another participant stated the following:

> *…why we always come back to disclosure? When people, when young women and men reach that level, they have a tendency to hide their medication because of being afraid of society and being afraid of stigma. They don't want people to know because they still want to go out and enjoy life; go work and do whatever the adolescent' are supposed to do. Because they gona become the adult and they gona have to be in charge, and they don't want to be stigmatized. So now they hide their medication and they become non adherent. Even though some of them are collecting, they still not using their treatment because of disclosure* (Counsellor – 10).

Participants reported that successful disclosure could facilitate transition and encourage adolescents to assume responsibility of clinic attendance, medication adherence and healthy behaviour. Participants reported that adolescents could show a willingness to acquire self-

management skills necessary for transition and be ready to take responsibility for their own health. Meanwhile, lack of disclosure could lead to adolescent's ignorance or denial of health condition as well as resistance to all treatments and process thus hindering the transition.

> *If there is disclosure in the family, they will be in a better position to offer the necessary support* (Outpatients sister – 17)

Nurses, doctors and pharmacists reported that parents often disclosed their child's HIV status to them at older ages to avoid stigma since they believe that children aged 10–12 years were not mature enough to keep the information confidential. A paediatric doctor stated:

> *…Confidentiality we have often seen mothers that are keen to disclose to a child. They don't explain to the child that is something to keep confidential, and because children are you know good-natured and not understanding stigma yet. We've had young kids of 8 or 9 going to class the next day saying oh by the way I have got HIV and having quite bad consequences* (Doctor - 24).

Participants reported that in their communities adolescents with HIV were stigmatized and discriminated against and they were not provided with support from their non-HIV-peers and the members of their community's one participant expressed it as follow:

> *Society can be very nasty because HIV is still the topic that is seen as a disease that if you are to blame you have a problem you are knowing* (Enrolled nurse assistant – 13).

Participants were concerned about the fact that both parents and certain family members involved in the care of the child were not aware of the diagnosis and status of the child because their mother never disclosed their status to them. As a result, the adolescent could not receive the full support from both parents and that constituted a barrier to transition and treatment.

> *The barrier will be now the mother is bringing the child, the mother did not also disclose. For the other partner the child is not sick why are you bringing him to the hospital it is extra expenses. That is a barrier for the child to progress effectively* (Outpatient sister – 17)

Doctors reported putting a lot of effort into educating their HIV adolescent patients about HIV and its treatment, but despite that adolescents continued to default. One doctor reported that it was disappointing and they felt that they had no control nor solution to stop adolescents from defaulting. Participants reported that it was always difficult for adolescents to continue to take their medication when they did not know the reason for their treatment. A counsellor aged 48 years old with 3 years of experience stated the following:

> *Those medications are not nice and no one will want to take them if he is healthy.*
>
> *Given that adolescent was becoming sexually active at an early age it was requested from parents that they disclose the diagnosis to allow their adolescent to adhere to treatment. Parents did not do that and it caused the challenge* (Counsellor – 10).

5.5 HEALTH SYSTEM FACTORS AFFECTING THE TRANSITION

5.5.1 Clinic environment (Day-to-day functioning)

Participants described the paediatric Clinic2 as a setting for general patients (patients of different age groups and with different health issues) with a noisy, crowded, filthy and warm environment with playful children. Participants described adults' clinic to be crowded, filthy, cold, quiet, with older people and with very busy healthcare-specific for infectious and chronic diseases (ICD). Participants' descriptions of the clinic environment corroborated my naturalistic observation findings. On a paediatric day, I observed that the waiting room was packed with

kids, adults, elderly people and adolescents. Some adolescents were accompanied by an older adolescent, an adult, a relative or a parent and other adolescents were alone. I observed that the clinic was crowded and noisy; some patients were sitting while others were moving into different rooms and children (age 6–9) were playing around. A 50 years old enrolled nurse stated the following in her interview:

> *Now if they come they realize it is another set –up is quieter, it is sometimes people on their phones after listening to me in the morning is like each of them is on their phone two or three will talk* (Enrolled assistant nurse – 13).

Another participant stated the following:

> *So this child is not sick and I am going to those places it is so crowded, it is dull it is full of old people and children screaming, and I have to wait for ages to be helped it is not nice it is not like I said before is not this you know a child there is no games like I said it is not environmentally friendly. It is not conducive for them you know you already have to change this person into you are not ill but you need to be on tablets and the screening to not become ill* (Outpatients sister – 17).

Participants reported that adult clinics hindered transition in that they were intimidating, busy and unfriendly spaces. Participants explained that transitioned adolescents were not familiar with the procedures of the adult clinic and that they felt scared and uncomfortable to engage in conversation. Further, participants reported that despite being confused about the procedures in the adult clinic adolescents refrained from asking questions out of fear of looking ignorant. A paediatric doctor stated the following:

> *I think our system is like not user-friendly and also moving into a new area the adult area setting, there you don't want to ask. You know sometimes we don't*

want to ask because we don't want to let people know that we don't know (Doctor – 24).

Another participant pharmacist stated the following:

Like teenagers, they are often getting the idea that they don't really want to be here. They like want to just be in and out they grab their pills and they are off. So they don't, they are very seldom to spend time asking questions. (Pharmacist – 22).

HCPs suggested that to facilitate a smooth transition, it was important to provide adolescents with clear explanations about the procedures in the adult clinic. However, participants indicated that it was not always possible to assist adolescents in this way given a large number of patients and the limited number of healthcare staff. One nurse stated*:*

So I think to understand how the adult clinic works being afraid of changing even when it is in a different clinic even though it is in the same clinic it is good to give clear explanation (Nurse- 20).

In Clinic 1, doctors, nurses, pharmacists and additional staff reported that the geographical position of the adult clinic could hinder the transition process. These participants explained that the facility was geographically separated from the general and outpatient clinic and that, the section for HIV patients was positioned in the middle of the building and unfriendly. HCPs suggested an integrated healthcare system in order to reduce stigma and facilitate the transition. A ward clerk stated:

I just think maybe space. I advise like now we are not making it you know people are inquisitive they ask why are these people sitting that side? Why are people, is not that we mark IDC side we go public we announce in the morning IDC most go this side general that side; but people find out and people tend to

> *ask. So maybe if we can have a building like that they don't get seen by general patients. Maybe something like that because now it is under one roof they want to know why you walking that side why people going that side. One side is general patients and on the other side it is HIV* (Ward clerk – 14)

In line with the above findings, I observed that in Clinic 1, the geographical position of the adult HIV clinic was not youth-friendly as it exposed patients attending the IDC to public judgement. I observed that the adult HIV clinic was separated from the general clinic and the outpatient room.

The adult HIV clinic was positioned in the middle of the building next to the pharmacy, facing the observation room. The second entrance of the adult HIV clinic was connected to the larger upper clinic area where general patients sat. I observed, patients coming from the upper general clinic and passing through the adult HIV clinic before getting to the pharmacy. Patients coming from outside the facility could also access the building and the general clinic or pharmacy passing through the adult HIV clinic. I observed that adolescents sitting in that area looked uncomfortable when they saw me walking in and sitting among them. I observed that adolescents immediately diverted their attention to their phones. Meanwhile other older HIV patients also looked at me and I felt like they were questioning my presence amongst them; maybe thinking I was one of the new HIV patients or someone who is looking for something. I felt as though anyone who sat here was automatically considered as an HIV patient. I felt that the geographical position could put the transitioning adolescents off, thus hindering their transition.

> *After observing I was now introduced to the staff and those sitting in the adult clinic could now see that I was not one of them. I felt that could have made them feel more uncomfortable having me sitting amongst them again lucky enough the rest of my day was reserved to interview and I could not continue the observation* (Observational notes).

A nurse in the adult clinic reported that adolescents who transitioned had a bond with their paediatric doctors and they were finding it difficult to cope with adult HIV doctors. Additionally, a doctor reported that, transitioned adolescents feared to meet with new HCPs and did not want them to look at their information. Participants reported that adolescents were fearful of losing their relationship with their previous doctors and clinic. As such the bond that adolescents shared with their previous doctors and previous paediatric clinic environment constituted a barrier to transition to adult clinic. One participant, a clerk aged 39 with 2 years of experiences stated the following:

> *Some will say but I so used to paediatric clinic can I not go back? I say you can't go back you've done so well you need to belong with this group now* (Ward clerk – 14).

Another participant, enrolled nurse assistant aged 50 years with 9 years' experiences express it as follow:

> *Some of them are very childlike, although they are 18, 19 they will ask me can I sit on the other side because it is mostly adult today. So they want to go back and sit in the paediatric side they are all sitting together but it's like they think if we change the date because now if you have to change it to a Monday now I am the only child here; I'm young, I'm the only youngster, I'm not an adult can I sit on the other side?* (Enrolled nurse assistant – 13).

Participants in Clinic1 reported that adolescents perceived the adult setting to be stigmatising and felt uncomfortable and shy to sit in adult setting as it made them feel exposed as HIV positive. Additionally, participants reported that adolescents who were transitioned did not want to be identified as adult. For them being in an adult setting meant that they were no longer young. One pharmacist age 61 with 34 years of experience express it as follow:

> *I can just think there will be mixed feeling because you want to be an adult, but now it is different because in the paediatric clinic you are treasured and now out of a sudden you are transferred to adult clinic so it is a whole different atmosphere. So it will be like emotional bittersweet, I want to be an adult but I am not that special like when I was a paediatric patient* (Pharmacist – 22).

5.5.2 Counselling as a facilitating factor for transition

Counsellors, doctors, nurses and pharmacists explained that counselling is a crucial part of the transition process. Counselling helps adolescents to adapt in the new setting, cope with the disease and self-manage their health. This theme represents the experiences from the HCP's perspectives.

Doctors, pharmacists, counsellor, nurses and registered sisters reported that adolescents transitioning from paediatric to adult healthcare were not accessing individual counselling services like adult HIV patients. Participants explained that only adolescents with issues related to medication non-adherence and social issues were usually referred for counselling sessions. Additionally, participants reported that counselling was not necessarily appropriate and adapted to the specific age group. Further, participants reported that the content of these counselling sessions was not sensitive to adolescents' personal experiences. Doctors, sisters and nurses reported that they continuously provided brief counselling to adolescents in their care as a way to keep them motivated and adherent to treatment. Doctors, nurses and sisters reported that transitioning adolescents were well aware of their health condition since they were seen in paediatric for many years and during those years they continuously receive counselling. A pharmacist explained that:

> *I think we need to take the person as a newly diagnosed and just make sure to take the person to one on one counselling. Make sure they understand, give the*

chance to speak in private with the counsellors where they can have a safe environment where they can speak, ask questions (Pharmacist – 22).

Participants reported that one-on-one counselling was an important component for transitioning adolescents. They explained that individual counselling could help in reinforcing previous memories of counselling acquired in paediatric clinic and gauge readiness and maturity of the transitioning adolescents. Alongside, counselling could also help to prepare adolescent to become independent and able to self-manage their health. Nurses, pharmacists and a doctor suggested that both transitioning adolescents and their families should be provided with consistent individual counselling sessions. Pharmacists traced the importance of providing counselling in the language of proficiency of the adolescent to ensure a better understanding of their medication prescription. Doctors, nurses, counsellors and pharmacists understood the term counselling differently. Counsellors, doctors and nurses referred to counselling as a therapeutic session, while pharmacist's emphasis was more on explaining doses and medication.

5.5.3 Disruption in the continuity of care

In both facilities, nurses, doctors, pharmacists, counsellor and registered sisters reported that they were challenged by time, a large number of patients, shortage of staff and according to them those factors could put off or demotivate the transitioning adolescents and hinder transition. Participants reported that they could not give enough attention or spend enough time as they have other clients to serve and other work to do. For example, one healthcare professional explained that they were only three sisters and they have to manage 80 patients per day amongst them. The above report was in line with my observational data. In clinic 2, I observed that, the total patients were between 70 and 80. However, the clinic had two pharmacists; one doctor treating both adults and paediatric HIV patients; one sister, two nurses treating both Paediatric and adult's HIV patients; two staff nurses doing observation with both paediatric and adult HIV

patients; one nurse treating only HIV infected mothers and babies and one HIV counsellor. A pharmacist in Clinic1 stated the following:

> *When we are so busy health workers we will seem like we don't have time to answer your questions because we are running around and we don't always give the attention that you need* (Pharmacists – 22).

Another participant, a doctor in clinic1 stated the following:

> *I think the way adult medicine is practiced is a lot less like that of paediatric so far, for example, we keep track on those who do not show-up in paediatric, we follow-up to check adherence but in adult clinic there is no such things, too many patients make it impossible to keep track on those who don't follow-up. It is adult medicine, there is no room for adolescence medicine* (Doctor – 4).

Adolescents who arrived late at the clinic could not always be helped before other patients who were there earlier; they had to wait in the queue. Participants reported that adolescents felt discouraged to continuously miss their activities, not be able to keep up with their responsibilities or with their school work. As such, long waiting hours and the perceived rude attitude of certain workers led some adolescents to default or give up on their treatments thus hindering their transition. One healthcare professional sated the following:

> *So I think that the barrier is there because the pharmacy is very strict, I don't blame them because there are also rules at the pharmacy if you didn't come to pick-up your medication there is a problem* (Nurse-6).

Another participant stated the following:

> *I think the pressure is very much higher, so we don't always have the time to be so nice. So the staff are so busy with a lot of things and it's difficult for them to*

> *allocate enough time which is actually needed like they need that but unfortunately* (Pharmacist- 17).

The nurses, doctors, pharmacists, counsellor and registered nurse reported experiencing challenges with the adolescents, mostly those around the early teenage (13, 14, 15, 16 years). Those challenges included refusal to have blood drawn, refusal to take medications and refusal to attend clinic appointments and impatience in the waiting room. A doctor in Clinic2 stated the following*:*

> *Well I think the one thing that comes to the forth is that they don't like to wait, they are in hurry they tend to be very in hurry so in their mind the clinic is still the place where the old people come I mean if we could have more flexibility in term of you can come in the afternoon after school. Whereby they can receive those adolescents any time when they come* (Doctor).

Nurses and doctors reported that it is a challenge for HCPs to keep adolescents on treatment once they reach 14 or 15. Participants explained that adolescents deliberately refuse to come to the clinic and were not compliant with treatment. Healthcare providers explained that caregivers reported that their children refused to take their medications and did not want to attend clinic because they did not know why they should and because they were tired of their treatment. HCPs reported that adolescents with rebelling attitude were difficult to transition and those that transitioned were more likely to default and be lost to care. One participant nurse stated the following:

> *The challenging thing is when the child is insisting is refusing for the sisters to draw blood from him or from her because she does not know why she must be drawn blood* (Nurse – 1).

Another participant stated the following:

> *The patients that we struggle with, the ones that we have to try and get to take the treatment when they don't want to. The reality is they end –up falling ill and passing away [when they transition?] before even so a child that is 12, 13 years' old that is not taking their treatment we do have a lot of them and is very sad they don't survive until they are 18 that is the reality* (Doctor – 24).

Doctors, pharmacists and nurses reported that they were challenged by the migration of families. They reported that due to certain socio-economic factors caregivers have to sometime migrate with or without their children. Adolescents who migrated with their caregiver were sometimes transferred out of their usual facilities. An adolescent who was left with family members or relatives remained in their usual facility. In both cases, those adolescents were difficult to treat and to follow-up. Migration prevented healthcare providers to continue treating or following up *the* HIV adolescent; it hindered treatment adherence, promoted defaults and stood as a barrier to transition. One participant expressed it as follow:

> *They tend to migrate a lot to Eastern Cape or where ever. So sometimes that is an issue when the family goes there, and kids are left there, and then other kids come back and you know they leave that one with a sibling, aunt or an uncle. So that is quite a problem if they go and six months or one year later they come back and things have changed (Pharmacist- 2).*

Another participant stated the following:

> *People move a lot so you will find a child now at this clinic, then after two months he transfers back and then the child is in there, he defaults and comes back. So there is a lot of moving and there is not enough continuity of care so that you really more focus on each problem and know each patient and help* (Doctor – 4)

Some pharmacists, doctors and nurses reported a gap in services as a barrier for transition. For example, psychological services were not provided and referral was almost non-existent; referral to social services was not on time and there were no follow-up system services for defaulting adolescents in adult clinic. One adult doctor indicated that not providing all the services could make HCPs to overlook the real needs of transitioning adolescents, thus hindering the transition. A paediatric doctor stated the following*:*

> *We are not beginning early enough to getting them the help that they need with substance abuse to get them to social worker. We definitely not picking-up enough to referring to proper avenues so that we can actually help them* (Doctor – 4).

> *Adult healthcare system is challenged by the follow-up of the adolescents' patients, there is a gap in tracing the patients that are lost to follow-up when they are managed as an adolescent or adult much than we have in paediatric* (Doctor – 24).

5.5.4 Social factors affecting the transition

5.5.4.1 Poverty and lack of resources

Healthcare providers identified poverty, lack of basic resources including (food, water proper housing adequate) and lack of employment and income as factors hindering transition. For example, participants reported that lack of food prevented adolescents from taking their medication and lack of taxi fare prevented them from attending clinic appointments. Participants reported that poverty and the socio-economic imbalance in South Africa had a negative impact on both treatment and transition in HIV- infected adolescents coming from underprivileged communities. A pharmacist aged 58 years with 14 years of experience stated the following:

> *Sometimes there is no food at home those things can affect that child; everybody knows that he is now big. Now you can take the medication on your own and there in these circumstances, there is nothing to eat. Sometimes these tablets have side effects, and now the child is not really informed. That will make the child sometimes when they come at that position they dodge make like they drinking they throw it away. Their viral is going down, when you ask them are you really drinking the tablets sometime they will say no because I can't swallow that they are very big* (Pharmacist – 20).

Another participant doctor in clinic1 stated:

> *Mothers earning basic income have to choose between bringing their child to the clinic and missing a day salary and run a risk to lose their job. Or going to their job and have enough money to put food on their table; is very rarely that the mothers are deciding I don't want to attend the clinic, there is always something that is out of their control* (Doctor – 24).

A registered nurse and a paediatric doctor in clinic B reported that the socio-economic imbalance of South Africa hindered the transition process in that, parents of HIV adolescents have to go early to their work and come back late, some have to work very far and some have to work different jobs. As a result, their children/ adolescents were left without supervision in term of their treatment and education necessary to promote healthy transition. A sister in the adult clinic stated the following:

> *So now we have to build right so, for me, for example, we need to address that a lot of our parents have to work three two or five jobs and whatever and shifts, where is the centre that I can put my child in? How? how the government is accommodating those parents a safe environment* (Outpatient sister – 17)?

Doctors, nurses and pharmacists, reported that the lack of youth centres in the community where HIV infected adolescents live was hindering transition. They reported that adolescents were withdrawn in the community because they did not have places where they could go and spend time learning or having fun. A doctor in clinic B stated:

> *I actually think what will really help, if we had an area where they could hang out together. And so for example, a room when we've got own room like what actually what they started at Tygerberg, it is called the Joshua room. And Joshua room kind of it is sort of pause on the process but the idea was to have an area with the bean bags, [and] football table [and] a TV and books and whatever where they can stop feeling I'm coming to the hospital. And while they are waiting they can play football with their friends rather than having to sit with all the masses of patients and been told you are just like everyone else so to have a safe place where they can socially interact with each other's I think will make a big difference* (Doctor – 24).

Further, participants explained that community-based centres for adolescents are necessary because they could promote the empowerment among adolescents. Participants explained that community centres could help HIV infected adolescents who are isolated to come out and socialize with other peers, do some activities have fun and receive education. Socialising with other peers could help in reducing the feeling of boredom and stigma and promote acceptance of HIV adolescents. A registered nurse explained that transition could be facilitated through a collective effort from communities and government to create a safe environment for transitioning adolescents.

> *Have this place where children can actually you know play with the computer or do their homework; they can watch a movie whatever it may be well obviously within your limits you know there are some games and then you've*

> *got your rooms. You have your computer like I said they love computers engages, so pool table. You have your health room, but you know that your health room is obviously confidential but it can be for diabetes it must be integrated* (Outpatients sister – 17).

Participants suggested that ward councillors should watch over their communities and work with the government to eradicate crime and promote safety of the community members including HIV infected adolescents. Alongside, nurses and doctors suggested that to facilitate transition ward councillors should work with the government to eradicate poverty, unemployment and lack of resources in the poorest communities in general and for HIV infected adolescents and their families in particular. One participant in clinic1 stated:

> *pressuring the government to have the staff there, to have the money there like I said, it must be you must help your ward councillors to be comfortable, because this is helping the youths' attitude. Is going to be about helping the youths and creating a safe environment* (Outpatients sister – 17)

5.6 SUMMARY OF CHAPTER

In this chapter, I presented the results of the present study. I began by outlining the sample demographics, after which I presented the thematic analysis findings, four main themes were (1) understanding and conceptualization of transition; (2) individual factors affecting transition; (3) health system factors affecting transition; (4) social factors affecting transition.

Participant responses unpacked various barriers and facilitators to transition at the microsystem, mesosystem, exosystem and macrosystem levels of the HIV-infected adolescent.

CHAPTER 6

DISCUSSION AND CONCLUSION

6.1 INTRODUCTION TO CHAPTER

The aim of this study was to identify and understand the barriers to and facilitators of the transition to adult care among HIV-infected youth from the perspectives of the healthcare professionals who work with HIV-infected youths. To achieve this aim, I set out four objectives. This chapter discusses the research findings according to these four objectives. The discussion starts with (1) the experiences of doctors, nurses, counsellors and pharmacists who offer HIV services to paediatric and adult patients regarding youths' readiness to transition to adult HIV care; (2) the barriers to readiness to transition to adult HIV care; (3) the facilitators of successful transition to adult HIV care, and (4) the contextual factors within the healthcare setting that may play a role in transition. These objectives are discussed under the following two headings: (1) Healthcare providers' experiences of youth transition; and (2) Factors affecting transition. These findings are subsequently contextualized by considering the available literature.

6.2 HEALTHCARE PROVIDERS' EXPERIENCES OF YOUTH TRANSITION

The first objective of this study was to explore the experiences of doctors, nurses, counsellors and pharmacists who render HIV services to paediatric and adult patients regarding youth transition and readiness to transition to adult HIV care. Participants spoke about what the word transition meant to them, as well as their experiences of their patients' transition to adult HIV care. The findings in this study showed that participants considered age and level of maturity important criteria for transition. Healthcare providers at both facilities reported that the ages of transition to adult care among their patients varied considerably, with some youth as young as 12 at age of transition and others at around 19 years old. While these ages range widely, these findings are in keeping with previous studies that reported wide ranges for the age

of transition. For example, in Europe, the age at transition is 18 years of age (CHIPS, 2016; Foster et al., 2009). In the United States of America, the age of transition ranges between 18 and 25 years (Tepper et al., 2017); and in the United Kingdom, age at transition ranges between 17 and 27 years (Kim et al., 2016). Evidently, it would seem that the age of transition to adult HIV care in resource-rich settings is somewhat older than the age of transition among South African youth. Van der Merwe (2008) reports that HIV-infected youth in South Africa transition to adult care at age 13 years. However, the authors did not provide a cut off age for transition. Moreover, participants in this study demonstrated a lack of consensus on the age of transition.

Participants in this study lacked consensus regarding the definition of the phrase, "transition of care". Some participants referred to transition of care as a change of medication regimen, some referred to it as a change of clinic or a change of doctor, and others were not familiar with the term, or could not provide a clear definition. In the literature, various definitions have been provided for transition of care. For example, in their study, Judd and Davies (2018) defined transition of care as a process where children with perinatal HIV are generally seen in paediatric clinics and then transferred to adult clinics in the same or different hospitals (Judd & Davies, 2018). Similarly, Knauth et al. (2006) define the phrase as a process during which adolescents and young adults with chronic childhood illnesses are prepared by healthcare providers to take charge of their lives and their health in adulthood (Knault et al., 2006). Also, Blum et al. (1993) define transition as: "The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems" (Blum et al., 1993, p. 570). These definitions illustrate that transition of care is generally considered a process of change that takes place. The general lack of understanding or familiarity with this phrase among participants in this study may be suggestive of there being no clear process of transition applied in these healthcare settings.

Indeed, these findings resonate with South African literature that shows a lack of policies on transition of care in South Africa (Kung et al., 2016; Stefan & Van der Merwe, 2008). The lack of a clear transition policy means that there is no planned process for assisting healthcare providers with preparing adolescents for a shift in care and change in a healthcare provider. There is some evidence to suggest that without a carefully planned transition process, adolescents may default or disengage from healthcare (Dahourou et al., 2017; Mark et al., 2018). In the absence of transition policies, participants reported using some of the following criteria to determine transition readiness: age (between 12 to 19 years); weight above 35 kgs; level of maturity, consistently good adherence to ART and a consistently suppressed viral load. These findings are echoed in the broader literature, demonstrating that a lack of standardized policies on transition made it difficult for healthcare providers to determine transition readiness among HIV infected adolescents (Badejo et al. 2018; Lam et al., 2017; Mark, Taing, et al., 2017; Maturo et al., 2015; Tepper et al., 2017). Further, in settings where transition policies do exist, studies have shown that these policies had varied definitions of transition and had different transitions processes. Healthcare providers mostly agreed that successful transition was dependent on good clinical and behavioural outcomes (Bundock et al., 2011; Hussen et al., 2015).

Despite no clear policies on transition, participants in this study reported several shortcomings of current methods of transition used in their healthcare facilities, including whose role it is to prepare HIV-infected youth for transition. Healthcare providers who work in adult HIV care reported that parents and paediatric healthcare providers are responsible for preparing the youth for transition. However, as these participants reported, this was not the case. Participants reported that as a consequence of poor preparation for readiness to transition many adolescents who sought their services were confused and sceptical towards a change of clinic and treatment. As shown in the literature, readiness to transition is determined based on an assessment of whether or not specific transition barriers have been addressed (Hussen et al.,

2015). Assessment for readiness is preceded by educational and training programmes, delivered to the adolescents and their families (Campbell., 2016; Straub & Tanner, 2018). Training programmes include but are not limited to self-management skills, understanding of medication and knowledge of the disease (Campbell, et al, 2010; Vijayan et al., 2009). Results from these studies have shown that assessing patients before transition is beneficial because it allows the identification and target of anticipated transition barriers, decreases anxiety for the transitioning adolescents, their family and improves transition readiness.

Participants also spoke about the lack of proper handover of adolescents between paediatric and adult healthcare providers as a further barrier to transition. Participants explained that a proper handover would include a detailed written account in the patient's files of the transition procedures that have been undertaken and an account of what and who has been involved in the transition process. In addition to the current practice of verbal handover from paediatric to adult services, as well as what the adolescent knows about the transition. Participants also suggested that a proper handover should start with early interaction between adolescents and adult healthcare providers – i.e. that adolescents and their adult healthcare providers should meet before the transition to become better acquainted with one another and to establish trust. To facilitate these interactions, participants suggested that paediatric doctors should introduce regular meetings between paediatric patients and adult healthcare providers when adolescents reach 12 to 15 years of age. Putting measures in place to better acquaint adolescents with their adult healthcare providers is especially important at healthcare facilities that lack integrated healthcare services. The findings from this study showed that doctors from the facility with separate adult and paediatric healthcare services felt strongly about such planned meetings. These findings are consistent with a recent study demonstrating that the shift from paediatric healthcare providers to adult healthcare providers is more noticeable and anxiety-provoking when adolescent have to move into a separated adult clinic setting. (Judd & Davies,

2018). The findings in this study seem to show that, although shifting into a separate clinic is anxiety-provoking, it may be advantageous in that adolescents can be made aware of their real diagnosis.

Participants reported that amongst adolescents at the cusp of transition, independence and self-management skills were key facilitators of transition. Participants reported that in terms of self-management skills, healthcare providers and parents should collaborate and gradually prepare adolescents from the ages of 14 to 15. For example, in the early stages, caregivers could sit out of consultations and allow their adolescent to engage with their paediatric doctor in private. These findings are in line with a study by Sharma, Willen, Garcia and Sharma (2014), indicating that preparedness of youth to transition to adult care required more autonomy and enhancement of independence. Further in this study, improved communication at an early age between children with HIV and their caregivers, and between healthcare providers and adolescents, was identified as a facilitator for transition. Healthcare providers' suggestions on how to approach communication included: caregivers discussing programmes on HIV (with their children) and discussing topics related to HIV, showing trust in their child, and making them feel important. Through these activities, children would have increased knowledge of their disease throughout their growth and could ease transition.

In line with these findings, early studies by Cox et al. (2014) and Grey et al. (2006), demonstrated that effective communication and positive interactions within the family facilitate self-management, and promotes better health outcomes. Additionally, in this study participants suggested that healthcare providers should treat transitioning adolescents with respect, provide them with equal treatment, create a friendly atmosphere that allow adolescents to engage in communication and discuss their problems or ask questions. In keeping with these findings, a previous study has shown that maintaining open lines of communication between different

service providers, professionals, young people themselves, and their families can prevent adolescent to be lost after transfer (Campbell, et al., 2016).

The findings from this study seem to suggest that although communication between healthcare providers and adolescents is considered to improve the process of transition, its implementation within the healthcare setting may be obstructed by several factors such as limited consultation time, noisy environment, and large patient loads which places pressure on healthcare providers.

Finally, the lack of continuity of care was identified as a barrier for transition. Participants stated that the majority of HIV-infected adolescents were left to manage their care on their own without support after transition. Participants reported that often when left with little to no support, many adolescents in their care defaulted on treatment and had poor medical outcomes. Continuity of care was suggested by some participants as an important component that could facilitate compliance to treatment after transition.

Participants identified migration of families to different areas as a factor hindering transition. While some adolescents with HIV who migrated with their caregivers were transferred out of their usual facilities, others ran out of medication and could not be reached. Of these, some just stopped taking their medication. Migration prevented continuity of care and hindered follow up, treatment adherence and promoted defaults. As mentioned previously, continuity of care ensures the provision of coordinated care and services over time and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances (Meiqari, Al-Oudat, Essink, Scheele, & Wright, 2019).

Participants reported that continuity of care could be achieved only if caregivers, healthcare providers, community members, churches, schools, and government, could each take responsibility for the health of youths with HIV. Participants in this study explain that, by offering social support, caregivers and community members could encourage transitioning

adolescents to keep up with their treatment and clinic appointments. In a previous study conducted by Okawa et al. (2018) all lack of support from parents and healthcare providers was reported to cause depressive symptoms among transitioning adolescents (Okawa et al., 2018). Further, participants indicated that, through political will, governments could provide funding to implement sufficient programmes for youths, and healthcare providers could organize peers support groups/activities and develop more dedicated adolescent service. In keeping with these findings previous studies have also suggested that social support of transitioning adolescents could have positive impact on treatment adherence (Toth et al., 2018). In order to know if this is happening, we need data on who transfers or transitions, and what their outcomes are over time. To know how well this is happening, we need data on the quality of transition processes and services. Given that adolescence is characterized by emotional turmoil associated with risk-taking and poor decision making, continuity of care is important in allowing continuous mentoring and support necessary to limit the risk of treatment failure. However, findings from this study show that there is no system in place to help to track adolescents after transition. This in itself can prevent continuity to care at the healthcare system level.

6.3 FACTORS AFFECTING THE TRANSITION

The second, third and fourth objectives of this study was to identify the barriers to successful transition to adult care; the facilitators to successful transition to adult and observe the contextual factors within the healthcare setting which may play a role in the transition.

6.3.1 Individual factors affecting transition

As mentioned earlier, in order to facilitate the transition, participants suggested that both paediatric and adult healthcare providers organized meetings more regularly with the adolescents at an earlier stage to strengthen new therapeutic relationships, and become accustomed to the adult clinic environment before transition. In addition to this the findings showed that adolescents' close attachment to their paediatric clinics and doctors posed a barrier to transition.

Participants were aware that adolescents undergoing the process of transition seemed to view the shift from paediatric to adult care as a means for their paediatric doctors to no longer care for them. Participants reported that adolescents feared to lose their relationship with their doctor, and were not ready to accept adult healthcare providers. Consequently, participants reported that this break in the relationship resulted in some adolescents disengaging from care and defaulting on their treatment. The aforementioned is in line with Straub and Tanner's (2018) findings, which demonstrated that peri-natally infected children often develop strong relationships with paediatric providers, resulting in a sense of loss at transfer of care. Other findings by Fair et al. (2012), found that some adolescents who transitioned to adult clinics expressed concerns over leaving their current providers and having to establish new relationships. Further, participants in this study reported that adolescents' attachment to their paediatric clinic and doctor, was because they had a negative perception of the adult clinic. For example, participants reported that adolescents believed that transitioning to an adult clinic meant that they were no longer considered as young people, and they did not want to be identified as adults/older people. Previous studies have shown that the difficulties in forming relationships between adult providers and young people reflect the clash felt by young people in the adult setting (Le Roux et al., 2017). This clash was sometimes exacerbated by the fact that adult providers had high expectations of the adolescent with regards to readiness to transition, developmental capacity, and responsibility (Philbin et al., 2017). Given that, difficulties arise from leaving a trusted relationship, and having to build a new one, adolescents' attachment to their paediatric healthcare providers is not necessarily because they do not want to transition, but is merely related to the fear of change. As indicated by participants, adolescents' negative feelings (denial, anger, fear of the unknown, fear of the imminent transition) were observed as a result of the change. Participants in this study were aware that adolescents who experience these feelings

were difficult to treat, more frequently defaulted, were non-adherent, and were lost to care after transition.

Healthcare providers identified boredom with taking medication as a barrier to transition; and reported that, adolescents who complain about being too tired to drink their medication were more likely to default, be non- adherent and lost to care. In line with these findings, previous qualitative data from a study conducted in Zambia identified difficulty in managing medication and physical reaction to medicines as factors leading to ART non-adherence among HIV-infected adolescents (Okawa et al., 2018).

In addition, medication side effects constituted a barrier for adherence; nurses and pharmacists reported that some side effects such as dizziness and nausea caused adolescents to refrain from taking their medication went they were at work thus skipping doses.

Further, in this study, adolescents' desire for peer conformity was perceived by healthcare providers as hindering the transition. For example, in a study conducted by Toska et al. (2015), it was found that, out of 858 HIV-positive adolescents participants aged 10–19 years old, 52% female who had ever initiated antiretroviral treatment feared peer rejection and desire to be loved by their partners (Toska et al., 2015). Some participants explained that adolescents who were preoccupied with the differences between them and their non-HIV infected peers were more likely to stop their treatment and clinic attendances. In addition, the inability to participate in certain activities was also identified as a factor hindering an individual's transition. Other factors hindering transition included the desire to pursue one's dream in order to be at the same level with peers; the feeling that one was no longer sick, or the realisation of having a lifelong illness. These individual factors were identified as barriers to transition by healthcare providers. As indicated by the participants, the above factors led youth with HIV to feel that they were losing their self-worth, "skipping their youth". Staying away from treatment was, therefore, a way to regain normality and acceptance from peers but in the meantime a barrier for transition.

Furthermore, in this study, some healthcare providers reported that adolescents who were inquisitive, extraverted (expressed their feelings and thoughts) and those who had a goal in life (had a dream) were able to adapt after transitioning. In line with the preceding, Loletha et al. (2017) demonstrated that HIV-infected youth who participated in life-goals individual and group activities sessions transitioned successfully (Loletha, et al., 2017).

Some participants reported that the developmental stage (i.e. adolescence) constituted a barrier to transition; while others indicated that the actual healthcare transition was a barrier. Others participants pointed out that, developmental stage, the positive HIV serology and the healthcare transition process were factors hindering transition. As mentioned in the literature, the healthcare transition coincides with the developmental transition, which is characterized by physical, hormonal, psychological, and neurological emotional maturation (Graber et al., 2016; Steinberg, 2014). As stated by the literature, adolescents' development stage can complicate healthcare transition (Philbin et al., 2017; Wiener et al., 2011).

Participants spoke about HIV knowledge as a facilitator to transition and conversely, lack of HIV knowledge as a barrier to transition. For many participants, the majority of people including adolescents with HIV and their non-HIV infected peers, as well as families and community members, were lacking HIV knowledge. Participants reported that, many people in the community where HIV-infected adolescents live perceived HIV as a shameful disease and believed that people got it as a result of their promiscuity. Consistent with these, previous research has indicated that, communities' members held negative and inaccurate views about HIV, including associating it with immorality and believing in transmission by casual interactions (McHenry et al., 2017). Others studies have also pointed out the same issue (Pantelic et al., 2018; Wiener et al., 2011). Further, participants reported that some HIV- infected adolescents believed there was a cure for HIV or that HIV was non- existent. Consistent with the preceding, early studies have found that, the belief that ART can cure HIV has been reported

amongst adults with HIV in a study conducted in South Africa (Nachega et al., 2005), and may prove problematic as individuals who hold such a belief may discontinue treatment when they feel 'better' (Muessig et al., 2015).

Participants reported that the lack of HIV knowledge prevented parents, peers, and families from providing the necessary support needed for transition. In keeping with this finding, previous studies have indicated that adolescents often lacked the HIV knowledge that could help them understand the need for a seamless transition and care continuity, including the potential individual- and community-level health implication (Philbin et al., 2017). It may, therefore, mean that knowledge of HIV is likely to induce support from parents and peers, once HIV adolescents feel accepted by their communities they could receive adequate support and transition smoothly.

Ignorance of the type of disease was pointed out as a barrier. Participants in this study reported that adolescents who did not recall that they were ill or did not know about HIV symptoms, find it pointless to transition and continue being on medication and were more likely to discontinue treatment. In response to the lack of knowledge, findings from this study revealed that lack of HIV knowledge was reinforced by a lack of awareness and educational programmes in schools, communities, churches, and particularly in rural areas. Participants suggested that implementation of regular awareness programmes on the knowledge of HIV and HIV treatment by healthcare providers could improve understanding and acceptance of the disease; which in turn may have a positive influence on the attitudes of adolescents with HIV.

In this study, many participants' responses indicated that adolescents with HIV knowledge did well both in treatment and transition compared to ones who did not. Adolescents' knowledge of the disease promoted responsibility for own health. Parents who understood the disease were responsible and involved in the health of their adolescent, they motivated, reminded them of medication times and clinic appointments. As such, parents were able to prepare their

adolescents to become responsible for their health. In keeping with the preceding, findings from Toth et al. (2018) suggest that social support and protection are essential in achieving positive health outcomes among adolescents living with HIV (Toth et al., 2018).

Further, participants reported lack of HIV knowledge and the belief that HIV was not existent led some caregivers and adolescents deny to their HIV status, and resort to partial or complete alternative treatments; causing a detrimental impact on their health. Based on the above, one can conclude that beliefs and disease-specific knowledge are closely related concepts, as identified in this study. Positive beliefs may create space for knowledge-acquisition. From the participants' responses, it appears that both beliefs and knowledge are strongly situated within the family and healthcare (microsystem) context and that it is influenced by interactions with caregivers, healthcare providers and peers. Positive beliefs and disease-specific knowledge are acquired through repetitive interactions with key persons (proximal processes) influencing the adolescent. In line with the above, previous literature have demonstrated that HIV-infected youth who have participated in happy-teens educational programmes, as well as support groups had a positive medical outcome after transitioning to adult care (Henwood et al., 2016; Straub &Tanner, 2018; Valenzuela et al., 2009).

Participants reported disclosure of HIV status as a key element for a successful transition. The majority of participants explained that a successful disclosure allowed adolescents to comply with their treatment. Successful disclosure also allowed families, friends and communities to provide adequate support necessary to facilitate the transition process. Participants agreed that plans for disclosure should take the maturity of the child into consideration; and that a good guide to begin the disclosure process was when the child started questioning about his health. In line with the aforementioned, previous studies by Lesch et al. (2007) and Wiener et al. (2007) and Vreeman et al. (2015) have suggested that HIV disclosure ought to be a process rather than a single event. Such a process should be initiated early and be

completed around the age of 12 before sexual activity begins as it may improve adherence and acceptance of the disease (WHO, 2011).

Alongside this, a good parent-child relationship and a stable home environment were identified as factors that could help facilitate disclosure. Participants in this study reported that adolescents with stable homes received support before and after disclosing, enabling them to more easily process the disclosure and accept their status. Participants in this study reported that, despite acknowledging the importance of disclosure, the complexity and ethical dilemma surrounding the rights of the adolescent and caregiver, decision and time to disclose, was seen to constitute a limitation. For example, participants reported that healthcare providers were not responsible for disclosure; their experience was that some parents/caregivers never disclose, and some adolescents who knew their status never disclosed. Consistent with these findings, a study by Cluver et al. (2015) has shown that adolescents who have not been disclosed their HIV status have three times the odds of non-adherence to ART (Cluver et al., 2015). Similarly, a study by Tanner's et al., (2018) has found that HIV- infected youth who reported higher levels of HIV disclosure-related stigma were less likely to have successful healthcare transition (Tanner et al., 2018).

6.3.2 Clinic environment

Findings revealed that adult clinic settings were perceived as hindering transition; participants pointed out an unfriendly environment (e.g. filthy, crowded, inappropriate infrastructure and position); an unfriendly atmosphere (e.g. noisy, intimidating); and an unfriendly structure (confusing, difficult to navigate) as preventing successful transition to adult care for youths with HIV. Rushed services, little time and attention allocated to transitioned youths, as well as negative attitudes of healthcare providers, were identified as further barriers to transition. Overall, these factors created fear, anxiety, and lack of trust, and prevented adolescents from adapting to adult services. Others studies by Kakkar et al. (2016), Lam et al.

(2017) and Tanner et al. (2018) have also found that adult clinics were not youth-friendly in term of environment, services and interaction with adult healthcare providers. However, to facilitate transition, participants in this study suggested improving the flexibility of clinics in terms of times and appointments, as well as the adoption of afternoon and weekend services. In line with this, a previous study by Kung et al. (2016) suggested the creation of a dedicated space in the clinics for transitioning adolescents.

Participants explained that adolescents who adapted easily to the adult environment transitioned well, and those who struggled to adapt ended-up defaulting. Those who adapted to the change of medication were able to do well, while those who did not want to change their medication were difficult to transition. Consistent with these findings, previous studies found that among adolescents who transitioned to the adult clinic, some adapted successfully while others did not (Miles et al., 2004). While some literature justified the lack of adaptation as emanating from adolescents' ill-preparation and lack of readiness (Sharma, O'Hare, Antonelli & Sawicki, 2014; Vijayan, Benin, Wagner, Romano & Andiman, 2009), other literature assigned the lack of adaptation to a shortage of trained healthcare providers in adolescent medicine (Hussen et al., 2015; Judd & Davies 2018; Tanner et al., 2018).

Several studies have traced the importance of identifying the needs related to the adolescents' developmental stage in order to accordingly assist through readiness and education. (AAP, 2018; Fair, Sullivan &Gatto, 2010; Wiener et al., 2011). In keeping with the preceding, specialized youth centres with an integrated healthcare system, with recreation and study spaces were suggested in this study as a model of facilities that would meet the needs of adolescents living with HIV, and facilitate transition. Alongside a more conducive internal architecture (beautiful interior design) was also recommended by a participant. Previous studies have suggested the implementation of youth-friendly models of care (with a programme to prepare

adolescents and trained HCPs in adolescents' medicine) as a way to facilitate (Dahourou et al., 2017; Loletha et al., 2017).

Participants reported a lack of psychosocial services in both clinics (Clinic1 and Clinic2). Specifically, the lack of appropriate referral mechanisms to psychosocial services constituted a barrier to transition; with failure to timeously identify and refer adolescents experiencing psychosocial problems. Additionally, participants reported the lack of educational materials adapted to adolescent needs. For example, participants felt that health education was not youth-friendly, and lacked innovation. To facilitate transition, healthcare providers suggested that younger staff should provide health education, and motivational speakers should be sometime invited to give a speech. Alongside, participants suggested art activities for HIV adolescent as well as anonymous telephonic communication system were HIV adolescents could call, ask questions or discuss their problems. Previous studies have also reported on the same issues (Dahourou et al., 2017; Mark et al., 2018, Straub & Tanner, 2018).

Lack of counselling for transitioned adolescents was identified in both facilities as a factor hindering transition. In line with the preceding, I observed in both clinics a shortage of healthcare staff and a large number of patients. I observed that both facilities did not have adherence counsellors, clinic1 had two paediatric doctors serving between 40 patients per day and clinic 2 had one doctor and three sisters sharing 80 patients per day. These findings are in line with early studies indicating that primary healthcare facilities are challenged to deliver high-quality services within a healthcare system that is lacking infrastructure and trained healthcare professionals and is facing an ever-increasing demand for healthcare services (Dahourou et al., 2017). In the above findings, services provided by the HCPs, the clinic environment, the caregivers and the HIV-infected adolescents are located at the microsystem level. The HIV-infected adolescents' are in direct interaction with parents, HCP's as well as other patients in the clinic. There is a bi-directional and mutual influence between all parties.

6.3.3 Social factors

Healthcare providers identified poverty, lack of basic resources including (food, water proper housing adequate) and lack of employment and income as factors hindering transition. In keeping with the preceding, a study by Hodes, Cluver, et al. (2018) and Shisana et al. (2008) have indicated that the aforementioned factors increase the vulnerabilities of transitioning HIV infected adolescents and lead to poor treatment outcome (Hodes, Doubt et al.,2018., Shisana et al., 2008). Poverty and socio-economic imbalance in South Africa had a negative impact on both treatment and transition of HIV-infected adolescents coming from underprivileged communities. In this study poverty and lack of employment are situated in the exosystem context of the adolescent environment and has an indirect negative influence on the health of the adolescent.

6.3.4 Stigma

As mention in chapter two, youth with HIV experienced three important stigma mechanisms, including enacted stigma, anticipated stigma, and internalized stigma (Mburu et al., 2014; Pantelic, Boyes, Cluver & Tabeng, 2018). These mechanisms are manifested in three predominant ways: prejudice, stereotyping, and discrimination (Earnshaw & Chaudoir, 2009). Stigma may negatively affect the psychological health, behaviour, and health outcomes of youth living with HIV, who are transitioning from paediatric to adult care, as much as it may limit support from family and peers (Coetzee et al., 2011). In the current study, participants reported that adolescents with HIV who experienced stigma did not want to be seen in the clinic, skipped their appointments and defaulted on their medication. Consistent with what precedes, a study by Dahourou et al. (2017) have found that HIV stigma causes avoidance of treatment centres and reluctance to attend support groups or utilize mobile health. In this study, few participants felt that support groups could reduce stigma among transitioned youth, and the majority were of the opinion that support groups were never a good idea. For example, one participant disclosed that the clinic had tried implementing a support group, but it was never successful; adolescents

refrained from participating as they feared that other HIV-peers will know their status. They feared that their status was at risk of disclosure, and that could lead to stigmatisation by their communities or schools. This is in line with Dahourou et al.(2017) demonstrating that stigma, along with perceived lack of acceptance by communities causes adolescents and young adults to not disclose their status (Dahourou et al., 2017).

Recent findings suggest that the public provision of ART in South Africa has not resulted in the social reconfiguration of HIV, from a heavily stigmatized to a manageable and 'normal' chronic condition (Cluver et al., 2018). Given that stigma induces a great amount of stress in youths living with HIV, this can result in negative coping strategies. In the current study a variety of coping strategies were identified, including secrecy of status, denial, anger, sexual risk-taking, hiding or dodging medication, deception, social withdrawal, and avoiding social support, all of which had different implications for their well-being. From the participants' responses, it appears that stigma and HIV are located within the adolescent, family, relatives, healthcare providers' HIV- peers, friends, neighbourhood (mesosystem) context. The interaction between the transitioning adolescent and the other systems healthcare setting, healthcare providers' family, friends and neighbours) is bi-directional in that one influences the other.

The above discussion has illustrated different systems within which barriers and facilitators to transition are located namely: The microsystem (HCP's, HIV-infected adolescents, parents/ caregivers', peers, friends and relatives that are close to the HIV-adolescents); the mesosystem (HCP's, staff in the clinic, clinic environment, peers, parents and caregivers); the exosystem (Clinic 1, Clinic 2, schools attended by the HIV-infected adolescents, communities in which HIV-infected adolescents live, places and type of work of caregivers and parent as well as unemployment and poverty). The macrosystem (lack of policies on transition, limited resources at the clinics). Alongside, the above discussion has an emphasis on various interactions and influences between systems and individuals as factors that could facilitate or hinder transition.

For example, the lack of policies and resources (located at the macrosystem) have a direct influence on clinics and HCP's (mesosystem). Consequently, lack of resources and policies influence indirectly on the quality of services provided by HCP's and on HIV-infected adolescents. For example, there is no process to guide transition therefore HCP's are making ad-hoc decisions for the transition.

According to Meleis' (2010), all adolescents go through various transitions including school transition, pubertal transition and for those affected by chronic illness such as HIV they also have to go through institutional transition. The current findings have demonstrated that HIV-infected adolescents have experiences the above mention transitions.

6.4 CONCLUSION

In this study, I sought to understand the barriers to and facilitators of transition to adult care among HIV-infected youth from the perspectives of the healthcare providers who work with HIV-infected youth. The findings of my study showed that healthcare providers had different understanding of the word transition to care. These participants understood transition to mean different things including a change of medication regimen, a change of clinic or a change of doctor, and others were not familiar with the term. Participants in this study identified a number of factors that could be barriers or facilitators of transition to adult care. The barriers to transition included the lack of transition readiness, the unfriendly clinic environment, the services gap, the lack of HIV- knowledge, the lack of communication, the adolescent developmental stage, the home environment and broad contextual issues (such as poverty, inequality, family breakdown, stigma and resource constraint). Participants made a number of useful suggestions to facilitate transition. Participants suggested the increase in the number of healthcare professional staff as well as employing younger staff. In order to provide adequate support and prepare adolescents for transition, participants suggested training and preparatory programmes. Participants suggested ongoing individual counselling sessions for transitioning adolescents as well as a

tracking system for defaulters in the adult clinic. Other suggestions included: the creation of youth-friendly clinics with integrated healthcare systems only for youths; equipment and material adapted for youths, support group for HIV-infected youths, training of healthcare providers in adolescents' medicine, creation of centres and programme for youth in their communities. Implementation of continuous HIV awareness programmes. Provision of resources for HIV- infected youth and their families. Findings highlighted the complexity of adult clinic healthcare providers to treat HIV-infected adolescents. Thus demonstrating the need for them to be trained in adolescence medicine. The findings also show that there is no specific clinic for adolescent, and the shift from paediatric (child-centred) to the adult clinic (person-centred) may be perceived as a threat to adolescent self-identity. Feeling that one does not belong to either paediatric or adult setting group can lead to treatment disengagement. Findings highlighted common issues that have been illustrated in previous studies. For example, the lack of policies on transition and standard procedure; the shortage of healthcare staff, clinics environment, stigma, and poverty. What appears to be new in my study is the challenges that healthcare providers experience with regards to migration and services gap in the healthcare system; the influence of homes environment, a new model of healthcare system (youth centres only for adolescents), adolescent desire for self-identity and peer conformity. The above findings suggest that limiting the risk factors and addressing adolescents' individual needs and broader contextual factors may be critical to advance research and practice in preventing barriers to transition to adult care.

6.5 LIMITATION OF THE STUDY

This study had a few limitations. Firstly, despite a good representation of different healthcare providers and the sample size that appeared to be adequate, using qualitative methods might have introduced bias into the data. The few disruptions occurring during the interview sessions might have also introduced bias in the data.

Secondly, the focus on the perspectives of the healthcare providers' workings with HIV-infected youths do not allow us to know what the opinions of the HIV-infected youths are, or whether they perceive the barriers to and facilitators to transition in the same way as healthcare providers.

Thirdly, although I ensured the identification of all themes relevant to the research questions to meet data saturation, the possibility of interviewing an extra participant could have added different new information in the study. As such, the data of this study cannot be considered to be an unquestionable complete representation of the experiences and perspectives of healthcare professionals who work with HIV-infected youths in Clinic 1 and Clinic2.

Fourthly, while progressing in my research there was an inevitable change of interviews and topics of inquiry at a certain point. This meant that I focused on particular aspects relating to the research questions and potentially lost other aspects as a result. I had to let go of some information of participants' experiences in both the interviews and the data analysis in order to keep the focus on my research questions.

6.6 RECOMMENDATIONS FOR FUTURE RESEARCH

Futures research should focus on finding ways to adapt standardized policies on transition at the clinic levels and ensuring its implementation by the healthcare providers. Future research should also move from clinic-base HIV awareness programme to more broad awareness programme targeting families and schools. Caregivers and HIV-infected adolescents should undergo a training programme that prepares them to be ready for transition. Adult clinic healthcare providers should be trained in working with HIV-infected adolescents. Older HIV-infected adolescents (20–24) who have achieved goals in life should be trained as mentor for transitioning adolescents. Alongside support groups should be co-facilitated by HIV-peers who are knowledgeable about the disease and taking responsibility for their health. Implementing

tracking systems for adolescents both in paediatric and adult clinics is imperative to reach and support defaulters.

The proposed areas for future research include

- Exploring the views of HIV-infected adolescents with regards to what they perceive as challenging when they undergo the process of transition and suggestions to address these challenges.

- Identifying the psychosocial needs of HIV-infected adolescents before and after transition to adult care.

- Exploring healthcare systems structural issues that impact on the quality of care provided to transitioning adolescents and finding ways of improving services to prevent defaults in adult clinic.

- Exploring the experiences of parents and caregivers of HIV-infected adolescents with regards to potential barriers and facilitators of transition at the family and communities levels.

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APPENDICES

Appendix A: Demographic information sheet

Demographic questionnaire

Tick the answer that best suit you with an X

Gender

o Male

o Female

Participant age: _____

Participant name and surname: _____

Participant occupation: _____

Participant first language: _____

Start time: _____

End time: _____

Years of experience in this occupation: _____

Appendix B: Semi-structured interview

1 Can you tell me about your experiences of providing HIV treatment and care to youth at your facility? [Probe: Can you tell me about the services that you provide to HIV-infected youth? In your experience, what has been the most rewarding aspects, what has been the most challenging aspects of your work with HIV infected adolescents?]

2 I am quite interested in the transition to adult care that HIV-infected adolescents undergo here at your facility. How is the transition process usually handled? [Probes: At what age are adolescents transitioned to adult HIV care here? And what has been your experience of the transition process? Which policies or strategic interventions have been implemented here to facilitate transition? What has been your experience with these policies (explore useful aspects, short-comings, suggestions for improvement)?

3 What do you think has been the experiences of adolescents who are transitioning (or have already transitioned) to adult care?

4 Can you perhaps elaborate on what you think enables effective transition from paediatric to adult care of adolescents living with HIV? And explain why you think these things are important?

   a For example, if you were to consider the adolescent at the individual level – what characteristics of the adolescent would you deem necessary to facilitate transition?

   b If you were to consider the adolescent at the family level -what characteristics of the family will you deem necessary to facilitate the transition?

   c If you were to consider the adolescent at the health system/services level - what characteristics of health system/services will you deem necessary to facilitate the transition?

d If you were to consider the adolescent at the external/societal level- what external/societal characteristics will you deem necessary to facilitate the transition?

5 Can you please elaborate on what you think are the barriers to effective transition from paediatric to adult care of adolescents living with HIV?

a For example, if you were to consider the adolescent at the individual level – what factors will you perceive as barriers to effective transition?

b If you were to consider the adolescent at the family level - what factors will you perceive as barriers to effective transition?

c If you were to consider the adolescent at the health system/services level-what factors will you perceive as barriers to effective transition?

d If you were to consider the adolescent at the external/societal level-what factors will you perceive as barriers to effective transition?

6 In your opinion, what is needed to overcome thebarriers to effective transition?

7 Do you have any final thoughts on the topic that you would like to share with me?

8 Thank you for your time.

Appendix C: Observation schedule

Date of observation	Location	Purpose of the observation	Observer
Twice a week	The waiting room of the clinics.		Sylvie Mbebe

Time		Observed
Mornings during working hours. Three days for paediatric clinic Three days for adult clinic	Coming and going of youth Whether it is a busy day or not The interaction between healthcare and youth in paediatric and adults' setting The interaction between family and youth in paediatric and adult setting The interaction between *youth and adults*' patients Interaction among youth. In paediatric and in adults' clinic settings. The rapport between healthcare and youth in paediatric and adult setting. Service delivery in paediatric and adult setting	Youths Nurses Counsellors Doctors. Others people Clinic environment

Appendix D: Consent form

Dear healthcare professional,

My name is Sylvie Mbebe and I am a master's student at the Department of Psychology /faculty of Arts and Social Sciences/Stellenbosch University. I would like to invite you to participate in a research project entitled**: Barriers to and facilitators of the transition to adult care among HIV infected youth in the Western Cape**.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

- **Purpose of the study**

The purpose of this study is to develop an in-depth understanding of the barriers and facilitators that exist in the transition to adult care from the perspectives of healthcare professionals working with HIV infected youth.

- **Are there any risks involved in taking part in this research?**

This is a low-risk study. I do not anticipate that any questions will result in marked distress, however, if any particular question makes you feel uncomfortable, you may choose to skip this question.

There is a risk of using your break or work time to participate in the interview, however you are free to stop the interview at any time if you feel that you have to return to your duties. We can reschedule another appointment to complete the interview.

- **Will you benefit from taking part in this research?**

You will not benefit materially from this study. However, this study will contribute to adding knowledge and will assist the medical sector, healthcare professionals and policymakers in the formulation of suitable policies and strategies to address the phenomenon under investigation

- **Will Anonymity and confidentiality be ensured?**

Yes, to ensure anonymity and confidentiality, code identifiers will be used in place of your name. Further, the information you provide to me will not be revealed outside the research group. Any reports or publications that emanate from this work will be completely anonymised.

The interviews will be audio recorded; all documents, research materials (audio-recordings, transcripts) and participants' information will be locked in a cabinet, and only myself and my supervisor will have access to these data.

If you have any questions or concerns about the research, please feel free to contact the researcher [Sylvie Mbebe] [email: mbebevie@gmail.com – Tel: 0719473908] and/or the Supervisor, [Dr. Bronwyne Coetzee;: email: bronwyne@sun.ac.za].

RIGHTS OF RESEARCH PARTICIPANTS: You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

You have the right to receive a copy of the Information(flyer) and Consent form.

If you are willing to participate in this study please sign the attached Declaration of Consent and (hand it to the investigator, place it in the box available, etc. as is appropriate to your project)

DECLARATION BY PARTICIPANT

By signing below, I ……..…..…….(participant full name) agree to take part in a research study entitled: **Barriers to and facilitators of the transition to adult care among HIV infected youth in the Western Cape**

and conducted by Sylvie Mbebe… (Researcher)

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I may be asked to leave the study before it has finished if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

- All issues related to privacy and the confidentiality and use of the information I provide have been explained to my satisfaction.

Signed on ……...……. Signature of participant……

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the principal investigator, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition, I would like to select the following option:

☐ The conversation with the participant was conducted in a language in which the participant is fluent
.

☐ The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

…… ……..

Signature of Investigator Date

Appendix E: Thematic analysis

For the purpose of this study, thematic analysis will be used to analyse the data. Thematic analysis allows for identification, analysis and reporting of patterns (themes) within data (Braun & Clark, 2006). The analysis will consist of six phases:

- Phase1 will require me to become familiar with the data through several readings and subsequently to transcribe the data while noting ideas (Braun & Clarke, 2006).

- Phase 2 will consist of generating initial codes. Interesting features of the data will be coded systematically across the entire data set in an order relevant to each code (Braun & Clarke, 2006).

- Phase 3 will consist of searching for themes. Codes will be classified into potential themes, gathering all data relevant to each potential theme (Braun & Clarke, 2006).

- Phase 4 will consist of reviewing the themes. Themes will be checked in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis (Braun & Clarke, 2006). The network ATLAS.ti will be used at this level to assist in theme selection.

- Phase 5 will consist of defining and naming the themes. An ongoing analysis will refine the specifics of each theme (Braun & Clarke, 2006).

- Phase 6 will consist of producing the report. A selection of vivid, compelling extract examples that relate to the research question and literature and a final analysis of the selected extracts will comprise the report.

One of the main advantages of thematic analysis is its flexible approach that can be used across a range of epistemologies and research questions. (Braun & Clarke, 2006). Observation data and interviews will be analysed side by side inductively through triangulation to better understand the topic under investigation.

Appendix F: Budget

The cost of the budget indicated below will be covered by me.

Designation	Price per unit/item	Total amount
Printing (quantity) 70 Flyers 80 consents forms 80Leaflets	-Flyers (R4 per flyer) - consent forms (R 2 ×1 form) Leaflet (R2 ×2pages)	Flyers= R280 Consents Forms= R 160 Leaflets=320
Transcription -Duration per recorded interview=60min -number of interviews= 30	-R 35 per minute (R35× 60 minutes ×30 interviews)	R=63000
Software Atlas ti		
Travel	Per day =R100x 30adays	Travel=R3000
Internet services	One year period = R10 ×1hour	Two years = R4000
Equipment for recording	R 1000	R1000
Editing of proposal	R 20c per word	
Editing of final Research Project		R10000
Publication		R20000

Appendix G: Timeline

- Start study: December 2017.
- End of study: December 2019.
- Recruitment: October 2018.
- Data collection: October- November 2018.
- Foresee for follow up interviews? two months: November-December 2018.
- Time taken to transcribe data: Two to three months: December- February 2019.
- Time taken to analyse data One month: March 2019.
- Deadline for chapters 1(March 2019); chapter 2 (March 2019); chapter3 (April 2019); chapter4 (May 2019); chapter5 (May 2019).
- Expected Graduation Dec 2019/March 2020.
- Dissemination (take results back to clinic).
- Publish a paper.

Appendix H: Flyer

Participate in Research

RESEARCHER

•

MRS SYLVIE MBEBE

0719473908

MBEBEVIE@GMAIL.COM

Are you a healthcare professional? Working with HIV infected youth in paediatric or adult care?

What do you think are the barriers to, and or facilitator to transition amongst HIV infected youth?

What is this study about?

The study is about gaining an in-depth understanding of the barriers to and facilitators of transition to adult care among HIV-infected youth from the perspectives of the healthcare professionals who work with HIV infected youth.

Who can participate?

Nurses, doctors, counsellors and pharmacists working with HIV-infected youth.

What will be requested from participants?

You will be requested to participate in one face-to-face interview that will be conducted at a convenient place and at a suitable date and time. It is estimated that the interview will last approximately 60 minutes. During the interview, relevant questions will be asked.

What are the benefits of participating?

You will be contributing in generating new information for potential use by healthcare professional, policies makers and enhance the health conditions of the HIV-infected youth who are in care.

There will be no incentive for participating in the study.

This research is for the purposes of a master's degree in Psychology (MA) at Stellenbosch University. This research is supervised by Dr. Bronwyne Coetzee (bronwyne@sun.ac.za).

This research has been approved by the Health research Ethics committee at Stellenbosch University (#xxx), and the Western Cape Department of Health (#xxx)

Appendix I: Contact permission slip

TITLE OF THE RESEARCH PROJECT: Barriers to and facilitators of the transition to adult care among HIV infected youth in the Western Cape

I,..... (full name and surname), would like to learn more about this study and how I may participate in this study.

I hereby grant permission for the investigator to contact me and explain this study to me. I may be contacted as follows:

Telephone number ……

Cell-phone number ……

E-mail ……

Preferred date of interview ……

Preferred time of interview ……

My occupation ……

I understand that by consenting to be contacted, I am not obligated to participate in the study.

Signature…….

Date…….

Details of principal investigator:

Sylvie Mbebe

Contact: 0719473908

Email: mbebevie@gmail.com

Details of research supervisor:

Dr. Bronwyne Coetzee

Contact: 021 808 3979

Email: bronwyne@sun.ac.za

Appendix J: Letters requesting permission to conduct research

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

MBEBE SYLVIE

Student Number 20487282

University of Stellenbosch

[redacted]

Date 20/04/2018

Dear sir/ madam

I Sylvie Mbebe, the undersigned, am a registered counsellor and Master's student at the University of Stellenbosch. In fulfilment of the requirements for the Master's degree, I must undertake a research project. My research project is titled: Barriers and facilitators relating to the transition of HIV infected youth to adult care in the Western Cape (Cape Town). This research project originated as a result of my interest in understanding the challenges experienced in the transition of HIV infected youth from paediatric to adult care and the continuum of adult care.

As such, the aim of this research undertaking is to develop an in-depth understanding of the barriers and facilitators that exist in the transition to adult care from the perspectives of healthcare professionals working with HIV infected youth. The project entails a series of interviews with paediatric and adult HIV healthcare professionals regarding the study title. The project also entails and observational phase, where I would like to if possible, observe the clinic on a "paediatric day" and observe the clinic on an "adult day".

With permission, I would like to conduct this research [redacted] This means that I would like to contact staff to participate in this study. Participation in the research is of course completely voluntary, and staff can decline to participate without consequence. Participants who provide written informed consent will take part in a face-to-face interview with me that will be conducted on site at an agreed upon date and time. It is estimated that the interview will last no longer than 1 hour.

For a better understanding I have attached the information leaflet about the aim of the study and its importance as well as consent forms, questionnaires and observation schedule. Very

soon I will be sending an ethical clearance certificate issued by the University of Stellenbosch.

Should you have any questions and queries not sufficiently addressed by me you are more than welcome to contact me or my supervisor, Dr: Bronwyne Coetzee,[email: bronwyne@sun.ac.za; 021 808 3979].

If you are happy for us to proceed with this research following obtaining the necessary ethics and Department of Health approval, please could you sign below.

Date of face to face conversation about study: 23 April 2018

Signature to approve research may commence following necessary approvals and permissions: _____

Thank you for your time and interest in supporting this research.

Kind regards

Sylvie Mbebe

Contact details: 0217624886 (work telephone number)

Cell phone number: 0719473908

Email: mbebevie@gmail.com

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY

LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

MBEBE SYLVIE

Student Number 20487282

University of Stellenbosch

[redacted]

Date 20/04/2018

Dear sir/ madam

I Sylvie Mbebe, the undersigned, am a registered counsellor and Master's student at the University of Stellenbosch. In fulfilment of the requirements for the Master's degree, I must undertake a research project. My research project is titled: Barriers and facilitators relating to the transition of HIV infected youth to adult care in the Western Cape (Cape Town). This research project originated as a result of my interest in understanding the challenges experienced in the transition of HIV infected youth from paediatric to adult care and the continuum of adult care.

As such, the aim of this research undertaking is to develop an in-depth understanding of the barriers and facilitators that exist in the transition to adult care from the perspectives of healthcare professionals working with HIV infected youth. The project entails a series of interviews with paediatric and adult HIV healthcare professionals regarding the study title. The project also entails and observational phase, where I would like to if possible, observe the clinic on a "paediatric day" and observe the clinic on an "adult day".

With permission, I would like to conduct this research [redacted] This means that I would like to contact staff to participate in this study. Participation in the research is of course completely voluntary, and staff can decline to participate without consequence. Participants who provide written informed consent will take part in a face-to-face interview with me that will be conducted on site at an agreed upon date and time. It is estimated that the interview will last no longer than 1 hour.

For a better understanding I have attached the information leaflet about the aim of the study and its importance as well as consent forms, questionnaires and observation schedule. Very

soon I will be sending an ethical clearance certificate issued by the University of Stellenbosch.

Should you have any questions and queries not sufficiently addressed by me you are more than welcome to contact me or my supervisor, Dr: Bronwyne Coetzee, [email: bronwyne@sun.ac.za; 021 808 3979].

If you are happy for us to proceed with this research following obtaining the necessary ethics and Department of Health approval, please could you sign below.

Date of face to face conversation about study: 2014/08/18

Signature to approve research may commence following necessary approvals and permissions: _____

Thank you for your time and interest in supporting this research.

Kind regards

Sylvie Mbebe

Contact details: 0217624886 (work telephone number)

Cell phone number: 0719473908

Email: mbebevie@gmail.com

Health impact assessment
Health research sub-directorate
Health.Research@westerncape.gov.za
tel: +27 21 483 0866; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201901_012
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie Van Zijl drive

Tygerberg Hospital

Cape Town

7505

For attention: Mrs Sylvie Mbebe, Dr Bronwyne Coetzee

Re: **Barriers to and facilitators of the transition to adult care among HIV infected youth in the Western Cape**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following person to assist you with any further enquiries in accessing the following sites:

[redacted] **Dr Werner Viljoen** **021 850 4704**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion date* which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 20-02-2015

Appendix K: Ethics approval

UNIVERSITEIT
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Health Research Ethics Committee (HREC)

Approval Notice

New Application

19/12/2018

Project ID :8477

HREC Reference # S18/10/209

Title: Barriers to and facilitators of the transition to adult care among HIV infected youth in the Western Cape

Dear Ms Sylvie Mbebe

The **New Application** received on 05/12/2018 20:31 was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 19/12/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: 19- Dec- 2018 to 18-Dec-2019

Please remember to use your project ID (8477)on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Departement of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/8477

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shana ,

Coordinator,

HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by ;the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.